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TAKING A CLOSER LOOK:
NEGATIVE REPORTING AND POSITIVE EXPERIENCES WITH HEALTHCARE FOR EAST AFRICAN REFUGEES IN BOSTON

by

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TAKING A CLOSER LOOK:

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WITH HEALTHCARE FOR EAST AFRICAN REFUGEES IN BOSTON

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ABSTRACT

This thesis explores the experiences of the health care system for East African refugees in Boston. I argue that refugee experiences lie on a spectrum ranging from inadequate to exceptional, and that by exploring what makes care both a negative and positive experience for refugees it may be possible to better serve the community. I conceptualize these experiences using the metaphor of a rope bridge: at the beginning, refugees are stuck in a formal structure that limits their movements and agency; throughout the middle, they are forced into a liminal space in which both their identity and experiences are made ambiguous; on the far end of the bridge; they have mitigated the deleterious effects of structural violence and liminality through practices involving selective acculturation, resilience, and self-verification. My participants reported being dissatisfied with the bureaucratic barriers to health care they encountered and with the power imbalances they felt when interacting with clinicians. They also spoke about the encounters they had with clinicians that made them feel listened to, cared for, and empowered. Much of the distinction between good and bad care relied on whether the patient felt like they were respected by their doctor, and whether they felt like they had a say in their own care and treatment. Due to the limited nature of this endeavor, further research is recommended on: 1) the role of memory in recovery; 2) liminality as it applies

to the resettlement experience; 3) maintaining and bolstering the assets that allow refugees to mitigate the effects of structural violence; and 4) in what ways the health care system is working for refugees, and how those can be expanded upon.

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LIST OF ABBREVIATIONS

AFRICOM……...United States Africa Command

ESL…… English as a Second Language

IHC…… Immigrant Health Center

IRB…… Internal Review Board

ISBCC…… Islamic Society of Boston Cultural Center

NGO…… Non-Governmental Organization

PA……... Patient Advocate

PN……. Patient Navigator

PTSD…… Post-Traumatic Stress Disorder

INTRODUCTION

I remember quite vividly the first time I felt what I can only describe as righteous indignation on behalf of someone I had never met. In my junior year of college, I was taking a class on the spread of Islam through Sub-Saharan Africa. This happened to be during the height of the panic over the spread of Ebola in West Africa. I and the other students came into class one day to find our regular class schedule set aside - our professor, who was from Senegal originally, wanted to discuss the role of language in the Ebola crisis. Public health officials, he said, were panicking because they could not understand why people were disregarding their notices and warnings advising local people not to come into contact with the infected or dead. Why were people not listening? One of the problems, explained our professor, was a disconnect in language. The official language of the country is French, written in the Latin alphabet, and official signs and warnings were written in French and Arabic. But for many people in the country, their local tribal language - such as Yoruba or Wolof - was the only one they could read or write, and they wrote it in a modified Arabic script called Ajami. Since the government did not want to recognize either those languages or the script they were written in, public health outreach programs had been putting up signs in the official languages, rather than signs in the languages of the local people. As my professor explained it, stubbornness on the part of the government and insistence on using the official languages over the local ones led to a massive information blackout for the people most in need.

As I heard this, I was appalled. How could the government willfully ignore the

realities of its people? Here was a situation where the solution was both obvious and simple, and yet due to bureaucracy and entrenched structure, a sizeable portion of the population was being ignored. I was shocked that this was a reality in which people have to operate: one in which their needs are secondary to the overarching agenda of their government. As clichéd as it may sound, it was that wave of righteous indignation that gave me my first true sense of what I wanted to do in the world.

I fell into studying East African refugees, and specifically Somali refugees, mostly by accident. I knew from an early stage that I wanted to work with refugees; although it is a population with which I have little to nothing in common, it is one in which I have always felt invested. The more hostile the political climate in the U.S. became towards immigrants and refugees, the more I felt that this was what I needed to do. In my home state of Texas, people talk often about the "illegals" crossing the border with Mexico. The conversation almost never fails to dehumanize the people and delegitimize their problems. The longer I spent listening to people ignore the terrifying plights of other humans and the extreme lengths they have gone to to reach safety just to reduce it to an "us vs. them" mentality, the more motivated I became.

As an undergraduate, I studied Kiswahili, and I knew that Boston had a large population of East African migrants and refugees. I thought, why not put my language skills to use? I began my search for a field site with the idea in mind that I would be working with Swahili people. When I came to realize that most of the East African

refugees in the Boston area are actually Somali, I became a bit discouraged. How would I help a population that I had not prepared to work with? Still, I was determined.

I went into the research itself with a broad set of questions I was sure would uncover what I was looking for. I was going to ask people to tell me their story, to tell me how they experienced health care, and to describe to me what it was like to be a refugee in such a hostile environment. After all, we were watching together the rise of a despotic megalomaniac with a particular hatred for immigrants; how could people not feel panicked? I had visions of myself listening and validating as people told me how they had struggled, how they felt persecuted, how they thought things should be different. Alas, since nothing worth having in life comes easy, my research —and more, importantly, my participants — had a surprise in store for me.

The literature I had read up to the point of my research that told me that refugees have bad experiences with the American healthcare system. I fully expected for my participants to tell me that they were upset, or disappointed, or felt they were not being cared for. And for some people, that was the case some of the time. But for many of the people I spoke with, their health care experience had been not only unobjectionable, but even amazing. I panicked. What was I supposed to do with data like that? What could anyone want with a thesis in which everyone is happy?

The longer I spent at my field site and the more carefully I listened and observed, the more clearly a pattern emerged. I began to see that while the refugees I had spoken to loved their clinicians, there were very real and frustrating structural issues at play that were making people feel lost or scared or hopeless. I saw that for every person working with this population, they wanted to do the best they possibly could with the resources they had been given, and that inadequate services or missteps along the way were not

necessarily attributable to malice or willful ignorance. I wondered where the disconnect lay between patients, doctors, and the medical system, and what opportunities there might be to bridge that divide.

The structure in which both refugees and the people who serve them operate – hospital structures, government structures, etc. - is calcified and rigid, and it limits their movements and their options. Despite this, there are countless refugees who have learned to navigate this unfamiliar territory, and who have built comfortable if not quite happy lives for themselves, despite the myriad obstacles and barriers they face from the moment they arrive in the U.S. Over time and with each new revelation, my research question shifted. I began to try and tease apart the nuances of the difficulties that refugees face. If people truly loved their clinicians so much, where did their frustration come from? What were the disconnects between patients and practitioners, and how could those be addressed without laying blame squarely on one party's shoulders? And, perhaps most importantly, what is going so completely *right*?

How can we conceptualize this reality in which people hold both the good and the bad? To borrow a metaphor from Dr. Fernando Ona, I think of the refugee experience as a rope bridge. At the beginning, it is anchored in rules and structure, and in this space peoples' agency is limited. At the end, it is anchored in positive experiences, and in the lives of refugees who have made it successfully through the process of resettlement and who have cultivated good and fulfilling lives. In the middle unanchored space, life is a bit more scary and ambiguous. People in this place can see that there is a way to make it to the other end, but no one can show them exactly how to get there. In this thesis, I follow

the refugee experience — as my participants have told it to me — across this bridge.

Goals and Significance of The Study

The major goal of this study was to explore the ways in which refugees experience healthcare and the resettlement process. Originally, this study was purely descriptive. I wanted to observe and report, and relay narratives from the refugees I spoke with. As the research progressed, and people began to tell me how happy they were with their doctors, but how frustrated they were with the system, I switched my focus to teasing apart the myriad reasons people are or are not happy with their health care, and what can be done to better people's experiences in the healthcare system. In the process, I learned a lot about resettlement and the everyday lives of East African refugees in Boston, and about the structural factors *outside* the healthcare system that affect things within it. By the end of this study, I really wanted to uncover some of the health and social assets that allowed for successful clinical and interpersonal interactions, and to find out what distinguishes the failures and triumphs of care in the eyes of the refugee population.

I argue that there are a set of commonly-held ideas of what refugee experiences and opinions "should" be, and that these ideas are considered status quo. This may result in an unconscious bias *in favor of* negative experience reporting. I am working from the assumption that I am not the only person in the United States that has spoken with refugees who are happy with their health care. The choice by authors and journals not to report on positive experiences may also come out of a desire to enact change, which is more easily accomplished when there is something wrong to point to. I believe that even

if the majority of refugee reports on their health care are negative, it is still important to include the voices who *do* find their health care satisfying. As well as being true to people's experiences, descriptions of positive interactions give health care providers examples of what can and has been done to make healthcare less stressful and more beneficial to refugees. In her TED Talk, "The Danger of a Single Story", Chimamanda Ngozi Adichie states, "So that is how to create a single story, show a people as one thing, as only one thing, over and over again, and that is what they become… I've always felt that it is impossible to engage properly with a place or a person without engaging with all of the stories of that place and that person." (Adichie: The Danger of a Single Story | TED Talk 2009)

Methodology

I set out to utilize a combination of participant observation, formal interviews, and informal interviews, as well as observation of focus groups. I began my internship at the Immigrant Health Center (IHC) in October 2016, and continued my internship there throughout the duration of my research. After obtaining IRB approval to conduct research, I began distributing flyers and approaching people in person at my field site in order to find participants. The people that I did end up speaking with were largely those that I either introduce myself to in person or that heard of my research through word-of-mouth. Although people did take my flyers, I did not get many responses to them; this may have been in part due to barriers such as a lack of access to a phone, computer, or email address, or due to the fact that the materials were not in a language they could read, as with the Ebola example my professor gave me.

The biggest setback in my research was the language barrier: I do not speak Somali or Arabic, and many of the people willing to speak to me did not speak English well enough to give informed consent. Due to the fact that this research was taking place at the Master's and not Doctoral level, I was not given permission to use an interpreter. Unfortunately, this resulted in my not being able to speak with a number of otherwise willing participants. However, I still ended the research with a wealth of observation data and a number of interviews that gave me spectacular insight into the refugee experience. My methodology and results will be discussed more thoroughly in my methods chapter.

Chapter Organization

In my first chapter, I situate refugees within systems and structures, using Johan Galtung's writings on structural violence and Erving Goffman's writings on social organization, stigma, and social performance as a framework. I use examples from my fieldwork and interviews in which refugees encountered barriers or obstacles to care, and I then discuss those experiences within the larger structural framework. This chapter illustrates the worst end of the spectrum of care: the heavily constrained and often ineffective services that people receive.

In my second chapter, I discuss the middle of the "rope bridge" that refugees traverse — the ambiguous, liminal space that they find themselves in for sometimes years at a time. In this chapter lie experiences where things were not entirely lacking, but may not have been effective either. The examples in this chapter are ones where people are being given services or their needs are being met, but only so far and for so long. Theoretically, I approach this chapter drawing not only from the framework of Galtung

and Goffman, but also on Victor Turner's theories of liminality and Michel Foucault's lectures on biopower, in order to explore the unique aspects of the ambiguous space.

In my third chapter, I discuss the ways in which refugees successfully acclimate to a new system and to a new society. The narratives in this chapter talk about positive interactions with healthcare professionals, feelings of hope and optimism, and the everyday successes of the resettlement process. I use theories of acculturation, resilience, and self-verification to discuss the ways in which refugees carve out good lives for themselves despite the challenges they face. This chapter is not necessarily about overcoming or eliminating obstacles, but rather about people figuring out how to be comfortable in a new system, and persevering in the face of adversity.

Outcomes and Impact

At the end of this research, I had collected a series of narratives and vignettes through interviews and observation that illustrated the wide spectrum of experience and emotion that East African refugees live during the process of resettlement and encounters with the healthcare system. The purpose of my research was not to produce generalizable knowledge or to give concrete recommendations about what *must* be done in order to improve a situation. Rather, I wanted to elucidate some of the situational nuances, and to tease apart the differences between problems caused by structure and those caused by interpersonal strife.

My hope is that this research will faithfully tell the stories of my participants, and will frame their experiences in a way that synthesizes the concerns of both clinical practitioners and social science researchers.

BACKGROUND

Despite the difficulties refugees face on a day-to-day basis in the United States, the refugees I spoke with reported being satisfied with their medical care. Even when faced with obstacles such as issues of getting to an office or a procedure not being fully explained to them, the people I have met expressed a general sense of happiness and contentment with their doctors. This contrasts with the overwhelmingly negative experiences reported in the literature. Much of this chapter will explore common themes in literature about refugees, such as the reporting of negative experiences and a sense of mistrust between patients and practitioners. The background will be split into four main sections: first, I will overview the quantitative approaches to refugee health both within camps and within the United States; second, I will overview anthropological perspectives; third, I will discuss common misconceptions within each; and fourth, I will review the theories that I make use of throughout this thesis.

The War in Somalia and Where People are Now

The current phase of the Somali civil war began in 2009 with conflict between the Federal Government of Somalia and various militant Islamist groups. After the withdrawal in 2009 of various militias and Ethiopian troops, the underfunded African Union peacekeeping force was left behind to support the government. Due to this and the capturing of the port city Kismayo, the tide turned in the civil war. At the heart of the conflict is an ideological mismatch: the militant factions believe that the current government is too accepting of the secular transitional government backed by the United States, known as the Transitional Federal Government. In March 2017, President Trump

gave more freedom to AFRICOM (United States Africa Command) to use in counterterrorist operations. Since then, AFRICOM has carried out various airstrikes; the exact number is difficult to come by (CNN 2018; Mazzeti et. al. 2016; VOA 2018).

The majority of Somalis currently in the United States arrived after the first breakout of civil war in the 1990s. As of 2015 there were approximately one hundred and fifty thousand Somalis living in the United States, with the most popular states for resettlement being Minnesota, Texas, and Ohio. Massachusetts also has a large population of Somali refugees, but Minnesota and Texas are by far the most well-populated states (Conor and Krogstad 2018; Radford and Conor 2018).

When I first started interning at IHC, I was talking to an IHC employee about where I was from. When I said I was from Texas, she exclaimed, "Oh! My cousin and his family live in Texas, I have a lot of family in Texas. I want to move down there so bad, they tell me it is just like Somalia!" I replied (a bit incredulously), "Really? How so?" and she told me: "Well people are so much nicer down there. They say hello to you and everyone is friends with their neighbors. There are lots of Somalis in Texas too. And everything is less expensive, plus it's so much warmer there! My cousin tells me that it even looks like Somalia — it is hot and sunny, and the land looks the same." I confess, I had not expected Texas to be so apparently popular in the Somali community.

Nevertheless, her statements were quickly affirmed and echoed by no less than two or three people in the office. This interaction gave me a small insight into what refugees value in the place they will call their new home; friendliness, a sense of community, and places that remind people of their home country. In the book *An*

Imagined Geography: Sierra Leonean Muslims in America JoAnn D'Alisera writes about the ways in which displace Sierra Leoneans express both a longing for their home country and a desire to build a community in America with other Sierra Leoneans. D'Alisera argues that immigrants maintain community ties through things like rituals and weddings, as well as national and international travel (D'Alisera 2013). This echoes what I saw at IHC: people both missed home dearly, and visited as often as they could, and simultaneously worked hard to connect with other Somalis in the Boston area and across the whole country.

The Quantitative Approach

Research on refugees both in and outside of the United States often employs an epidemiological or public health perspective. There are numerous publications about the statistics of health and of disease transmission in refugee camps - a quick Google Scholar search returned 1,360 papers from 2017 alone, and a search of public health articles returned 4,440 results. These quantitative articles tend to focus on what interventions are needed to make refugee camps safer, cleaner, and more viable in the long-term. Occasionally, long-held ideas of what refugee health "looks like" persist, even when new data suggest that trends may have changed.

Within Camps

Sometimes the statistics about a disease are technically correct, but a closer look at the phenomenon reveals something surprising. For example, following a Hepatitis E virus (HEV) outbreak in South Sudan in 2016, researchers re-examined sources of transmission. They found that, despite the assumption that HEV is transmitted through

contaminated drinking water sources, it was actually household samples that tested positive for HEV, suggesting another method of viral transmission (Guerrero-Latorre, Hundesa, & Girones 2016). The partially-right and partially-wrong analysis of a disease is not uncommon in public health; in the nineteenth and early twentieth centuries laypeople and professionals alike thought that malaria was caused by "bad air", and official recommendations on avoiding the disease were based on this understanding (Humphreys 2003, pp. 39-42). The history within public health and related fields of basing recommendations on inaccurate data underscores the need for a consistent re-examination of long-standing assumptions and knowledge.

In some areas of refugee and immigrant health, the right problems are being looked at in the wrong places. A review of studies about substance abuse in refugee populations found that most of the studies done took place in high-income areas, even though 80% of the world refugee population lives in low-to-middle income areas (Horyniak, Melo, et. al. 2016). In cases like this, the researchers were studying the right phenomena, but doing so in places that would give them misleading statistics about the issue.

A study of the health situations in camps on Lesbos island found that more attention needed to be paid to both dental health problems and mental health issues, as these were the most common complaints from the refugees. The study also argued that in order to give appropriate health care the camps needed to be transformed from "hotspots" into those designed for "long-stay situations." (Hermans, Kooistra, et. al. 2017). Because the camps were set up to be short-lived, there were serious issues with sanitation, and a

vaccination program had not been set up. In a related study, Cutler (2015) found that in Europe, "forgotten infections" are re-emerging as a result of the sudden influx of refugees and the untenable situations in "pop-up camps". Cutler points to causalities such as lice and dirt as reasons for the re-emergence of infections. Among the recommendations he makes to combat this phenomenon are the need for de-lousing and regular clothes washing, two things that do not occur in overcrowded and under-regulated temporary camps (Cutler 2015).

Within the United States

A study done in 2016 in Fort Worth, Texas with 994 participants found that risk of latent tuberculosis infection (LTBI) was *not* significantly increased among people who had lived or were living in a refugee camp, even in countries classified as having a high risk of infection (Kolasani 2016). However, another study done in Canada found that although tuberculosis is still a relatively small issue, foreign-born peoples account for 65% of all tuberculosis cases, meaning that the heavy burden of the disease is on populations that face added barriers to health care (Greenaway, Sandoe, et al. 2011). The latter study suggested that culturally sensitive approaches to tuberculosis screening, prevention, and treatment problems could relieve some of that burden. The portrait of tuberculosis among refugee populations is more complicated than simply "refugees carry and transmit tuberculosis".

Every approach to studying refugee health finds itself reflected in the policy surrounding refugee health care. The challenge for social scientists and clinicians is to integrate the quantitative data that informs policy immediately with the qualitative data

that can help policy makers ensure that programs and regulations are more effective in the long term.

Negative Patient Experiences

Negative experiences can take two forms: experiences with the system and interpersonal experiences. These negatives are much more commonly presented and represented in literature than positive experiences are; this may be due to a relative lack of people that report positive feelings about their health care or providers, or it may be borne out of an attempt to galvanize and prompt action. These are the types of experiences I expected to hear about over the course of my research, and in my experience form the base of knowledge of what refugee experiences with health care "look like."

Negative Experiences with Healthcare Systems

Various studies have found that barriers such as access to care, difficulty navigating an unfamiliar healthcare system, and the inability to handle finances (e.g. using a co-payment system) are the biggest reasons that refugees fail to access necessary healthcare (O'Donnell et al. 2016; Robards et al. 2017; Chang-Muy and Congress 2016; Colucci et al. 2015).

O'Donnell and colleagues (2016) found that in Europe, entitlement to care and pressure from outside forces such as austerity restricted immigrants' access to vital services. They caution that external pressures not be allowed to interfere with access to

services, and suggest that a strong "culturally sensitive" primary care system can help bolster and foster the access that refugees and immigrants have to health care systems.

Robards et al. (2017) undertake a systematic review of access to care among marginalized youth, and find that alongside the barriers to care faced by all youth, marginalized populations face compounding difficulties. They recommend that future studies consider the role of technology and technology access in the ways that young populations access and navigate the health care system.

These studies and others I have cited throughout this thesis underscore the myriad difficulties that refugees – and other marginalized populations – face when attempting to access the health care system. Financial and language barriers are two of the biggest deterrents, as well as resource restriction from outside sources such as political pressures.

Negative Experiences with Practitioners

On the interpersonal level, refugees and immigrants may have a hard time trusting their doctor or may have had experiences where doctors infantilize them or disregard their concerns, leading to a reluctance to interact with health care professionals. In addition, doctors occasionally relied on stereotypes of refugees, leading to a failure to focus on the individual patient, and this experience could result in refugee patients being wary of seeking treatment in their countries of resettlement, especially if national sentiment towards refugees and immigrants is unfavorable (Cheng et al. 2015).

Mancuso et al. (2015) found that there was a disconnect between how Karen refugees' doctors perceived their care and how they and their compatriots did:

> "…Although Karen refugee women expressed an overall satisfaction with and understanding of their perinatal care in Buffalo, interviews with Karen interpreters and doulas suggested that Karen women in fact had many concerns

and questions… participants' general reluctance to voice negative opinions about their care with the researchers echoed the women's conversations with their providers, who therefore viewed Karen patients as agreeable and easy-going."

I heard similar sentiments in my own research: that refugees are reluctant to question people they see as infallible or as authority figures above them.

A study focusing on unaccompanied adolescents' mental health care (Majumder et al. 2014) found that youth were reluctant to trust any sort of health care practitioner, due in part to their own culture's attitudes towards mental illness, as well as their experience with psychiatric care in their home countries. Interestingly enough, the authors of this study did not consider interactions with Western doctors as a potential reason for perceived reluctance to engage with mental health services.

The Anthropological Approaches

The field of medical anthropology relies upon participant observation for its critical understanding of the populations that it studies. In contrast to other health related research practices, participant observation and ethnographic research allows for a richer understanding of phenomena. Clifford Geertz's "thick description" is often cited as being the standard to which anthropologists aspire. Thick description is the practice of describing not just a person's behaviors or actions, but also the context that informs said person's actions (Geertz 1973; Ponterotto 2006; Mason 2017; Freeman 2014). Medical anthropologists use traditional qualitative data-gathering practices such as focus groups, one-on-one interviews, and surveys, but in addition to those things they also spend considerable amounts of time with a population, examining the underlying cultural

factors that influence the decisions that people make and how they interact with the world.

Qualitative studies surrounding refugee health care may focus on specific problems or cases, but more commonly address broader theoretical and contextual issues. Sometimes these studies are large, multi-decade projects that look at a large number of factors or sites; sometimes researchers use case studies to illuminate a specific phenomenon. Among the more theoretically inclined studies, common topics include biopower, somatization, and embodiment. The issue of control over both one's situation and one's own body is a recurring theme in refugee studies.

Aihwa Ong (1995) discusses "webs of power." She details the ways in which refugees and doctors operate within these complicated webs, and the ways that each group struggles for power both within and without the web. Ong points out that the doctors had absolute faith in biomedicine, and did not understand why the refugees would not trust them and, by extension, biomedicine. For the refugees, however, the issue was giving up control over their own bodies to a system with which they were not familiar (Ong 1995). These sorts of power imbalances become barriers to shared decision-making (Joseph-Williams et. al. 2014; Nimmon and Stenfors-Hayes 2016; Bending 2015). Researchers can trace some common complaints around refugee care back to this core issue. An example of this is noncompliance: whereas a doctor with complete faith in biomedicine might see little reason *not* to adhere to a treatment plan, a refugee confronting a new medical system may be understandably reluctant to take a medication that a doctor prescribed to them.

Research commonly discusses somatization, embodiment, and the various expressions of illness (Rohlof et. al 2014; Barkil-Oteo et al. 2018; Morina et al. 2018). Jennifer Carroll studied the ways in which Somali refugees conceptualized mental illness and how they dealt with it in both pre-war and current communities. She found that the refugees preferred community support and traditional medicine to biomedicine, because they felt that Western doctors did not understand the suffering they were going through. They also felt that biomedical solutions to the problem were not necessarily the best solutions (Carroll 2004).

Finnstrom and Soderhamn (2006) discussed the ways in which Somali women experience and conceptualize pain. The authors found that the Somalis were often expected to mask their pain outwardly, even as young as ages 6-8. They also found that most of the literature on pain and culture came out of the United States and was thus not readily applicable to other cultures (Finnstrom & Soderhamn 2006). These articles show that although current quantitative research is useful and illuminating, more descriptive or more culturally aware studies could be done. Other articles attempt to redefine or re-examine chronic pain and suffering (Williams and Craig 2016; Sturgeon and Zautra 2015; Lumley et. al. 2015).

Another major idea addressed is liminality (Wessels 2017; Beitel 2016; Boer 2015; Baird and Reed 2015). Arthur Van Gennep defines liminality as "a quality of ambiguity or disorientation that occurs in the middle stage of rituals, when participants no longer hold their pre-ritual status but have not yet begun the transition to the status they will hold when the ritual is complete." (Van Gennep 1906). This term has become

popular because of the way it embodies the refugee experience; they are people without a nation, without much legal protection, and often without a community. Refugees are both physically and metaphysically in a space where much of their sense of identity has been stripped away – leaving them "bare life" (Agamben 1995; Dines et. al. 2015; Holmes and Castaneda 2015; Katz 2017). This is, of course, a viewpoint brought in by people outside of this community and largely for people outside the community as well; none of my participants would have considered themselves or their lives "bare." Still, this theory and terminology provide an idea that I think is worth considering. This state of uncertainty is one that people find themselves in for sometimes decades at a time.

There are drawbacks to relying too heavily on one framework – Marwa Ghazali argues that the liminality framework often used to structure refugee health care fails to take into account how suffering is conceptualized by the refugees themselves. She notes that researchers need to look more closely at how violence targets identity, and how refugees then reconstruct that identity (Ghazali 2010). By listening and giving credence to refugees' own accounts of their suffering, researchers can mitigate this issue. In my own research, I endeavor to portray what my participants tell me faithfully, in order to minimize this phenomenon.

In his book *Wasted Lives*, Zygmunt Bauman argues that refugees are also seen as human refuse — wasted, superfluous, useless lives. They are "redundant populations." To quote Bauman:

> "The global spread of modernity has given rise to growing quantities of human beings who are deprived of adequate means of survival, but the planet is fast

> running out of places to put them. Hence the new anxieties about 'immigrants' and 'asylum seekers' and the growing role played by diffuse 'security fears' on the contemporary political agenda." (Bauman 2003).

We are seeing this played out now across the globe. Popular rhetoric tries to turn the issue into one of "us" vs. "them." (Van der Noll et. al. 2017; Steele et. al. 2015; Schmuck et. al. 2017). Marcia Inhorn and Gamal Serour have discussed the ways in which anti-Muslim rhetoric in the post-9/11 climate has negatively affected health care for Muslim refugees and immigrants. They found many barriers to healthcare access, including racial and religious discrimination, language barriers, and lack of cultural competence and sensitivity on the part of practitioners (Inhorn & Serour 2011). This article concisely shows the effect that the social and political climate can have on health care for real people. As I discuss earlier, people can embody suffering — such as the kind caused by living in a hostile political climate — and this can lead to more negative health outcomes for those people.

Common Issues and Misconceptions on the Part of Researchers and Clinicians

Many refugees face barriers in seeking health care, both in the United States and prior to their arrival. Refugees commonly spend anywhere from a few years to a few decades in refugee camps before their arrival in the United States. My focus is on East African refugees, specifically Somali refugees. A large percentage of this population has spent a considerable amount of time in Kenya or South Africa: anywhere from a year or two to decades of their lives (Lischer 2015; Esses et. al. 2017). Many of the children of the refugees I spoke to were born in these camps. Often, the care received there is cursory

– this is not due a lack of caring on the part of clinical workers, but rather the large number of refugees relative to the small number of available clinicians. When refugees arrive in the United States, they may not be accustomed to the level of biomedical care in which they are expected to take part. Adjusting to a new healthcare system that they are also attempting to navigate within a new cultural system leads to understandable growing pains, miscommunications, and disconnects. It is these that I am attempting to elucidate - to tease apart the various fallbacks and triumphs in the system of care for refugees.

Mental (Un)Health

One of the most common criticisms of biomedicine takes aim at the way biomedical doctors address mental health within refugee communities in Western countries. Foremost among these is the idea that refugees may conceptualize mental health differently than the biomedical community, and that they may express their mental health conditions in a way that looks different than what biomedical doctors may be used to. Thus, doctors need to understand the different ways that refugees may express pain, including looking at somatic expressions of mental anguish (Alemi, Weller, et. al. 2016;

Henry 2006). Expressions of pain may also look different in camps as opposed to post-resettlement.

The Massachusetts Refugee Health Assessment guide states that, "In studies with representative samples using self-rated scales, the prevalence of PTSD ranged from 9-86%." This subsection characterizes refugees as being "predisposed" to PTSD and clinical depression (Mental Health 3.4.3.) In a powerful critique of western biomedical practitioners' treatment of refugees' mental health, Derek Summerfield (1999) writes:

> "…for the vast majority of survivors posttraumatic stress is a pseudocondition, a reframing of the understandable suffering of war as a technical problem to which short-term technical solutions like counselling are applicable. These concepts aggrandize the Western agencies and their `experts' who from afar define the condition and bring the cure. There is no evidence that war-affected populations are seeking these imported approaches, which appear to ignore their own traditions, meaning systems, and active priorities." (pg. 1449)

The tension between what clinicians see as obvious mental illness and what refugees believe is natural suffering comes up again and again in both the literature and in my own interviews and participant observation (Clark 2014; Tran 2017; Jansen et. al. 2015). I discuss this further in chapter one. There needs to be more of an emphasis than there currently is on considering a patient's own worldview and conceptualization of illness.

Communication Across Differences

One of the more basic and yet also most complicated problems is that of cross-cultural communication, and not just translation (Kleinman 1978; Koh et. al. 2014; Epner and Baile 2012). A good translator, and one who is familiar with the cultural background of the patient, is no doubt an incredible boon. But there exists a deeper need for cultural understanding, especially in areas or even in specialties where doctors might not have had as much contact with refugees. There are layers to interpreting: first, the basic linguistic barrier; then, there are subtle differences in cultural expressions of emotion and

experience. These subtle differences necessitate having an interpreter who is not only fluent in the right language and has the vocabulary to be working in a medical setting, but who is also familiar enough with the patient's cultural group to help bridge the divide between patient and practitioner. A study done in Norway found that in an effort to be culturally sensitive, health care workers avoided asking patients about what they felt were sensitive subjects, such as sexual health and reproductive health, and in doing so the health care workers imposed "imagined cultural values" on those patients (Johansen 2006). Additionally, the practitioners may have missed out on valuable information from their patients. Often times, people will hear "culturally aware" and conflate that with cultural sensitivity, but as Johansen's study showed, the desire to be sensitive to someone's cultural values may actually do more harm than good if the person themself is not included in the narrative.

Kagawa-Singer (2003) has highlighted the ways in which communications between doctors and patients in the West are based off of a monocultural system that places the individual, autonomous body at the center of any issues, and that values open and direct verbal communication. In the process, nonverbal communication as well as family and cultural narratives can get pushed to the side or ignored altogether. There are three cultures involved when a patient sees a practitioner: the culture of the clinician, the culture of the patient and their family, and the culture of the system or organization in which they are all functioning. Kagawa-Singer points out that some cultural behaviors may appear maladaptive when viewed against the standard of a different culture, citing the example of differences in emotional responses to cancer between Japanese-American

and European-American patients. As stated before, clinicians need to take into account the culturally relative ways in which patients may express pain, both mental and physical, in order to fully meet their needs.

Theoretical Orientations

In this section I will outline the various theories that I make use of in the following chapters. Of those, the first and foremost is that of structural violence. Johan Galtung introduced this term in 1969 when he argued that violence is not limited to physical expression — killing, maiming, etc. — but that it can be also expressed through structure. Galtung asserts: "*violence is present when human beings are being influenced so that their actual somatic and mental realizations are below their potential realizations.*" (Galtung 1969, pg. 168). Researchers use structural violence theory when discussing phenomena like structural inequalities or prejudices; two common examples are state-level racism and food deserts. This theory helps explain things that happen at a level far above the individual, but that affect people on an individual level nonetheless (Rodriguez et. al. 2015; Rylko-Bauer and Farmer, 2016; Saleem et. al. 2016).

I use Erving Goffman's theories of the presentation of self and stigma to situate refugees within a social order. Goffman's *The Presentation of Self in Everyday Life* (1956) treats face-to-face interpersonal interactions as a sort of play in which people act out their roles through their appearance and manner. The "actor," as it were, attempts to conform to pre-established roles and maintain face. One example Goffman favors is the man tripping at a formal dinner party: he is trying to act the appropriate role of houseguest, and in tripping embarrasses himself. Those around him may pretend not to

have seen him trip in order to aid him in saving face.

In *Stigma: Notes on the Management of Spoiled Identity* (1963), Goffman writes, "Society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories… When a stranger comes into our presence, then, first appearances are likely to enable us to anticipate his category and attributes, his 'social identity'... We lean on these anticipations that we have, transforming them into normative expectations, into righteously presented demands." (Goffman 1963, pg. 2) Accordingly, when people present with an attribute or behavior that distances them from the "norm," they are classified as a member of the non-normative group, and this classification is a stigma. The stigmatized are then rejected and shunned from the group. In this way, refugees are classified as visibly different and are subjected to social rejection and discrimination.

In addressing stigma among refugees, I use self-verification theory, first put forward by William Swann in his article "Self-Verification Processes: How We Sustain our Self-Conceptions" (Swann 1981; Xu et. al. 2017; Upal 2015; Singh 2017). Swann argues that once people develop firm views of themselves, they will seek out experiences and relationships that validate and reinforce those views. He writes, "... people are motivated to maximize the extent to which their experiences confirm and reinforce their self-views." (Swann 1983). Self-verification is not necessarily positive; people who hold negative views of themselves will seek out relationships that confirm those views (Swann 1992). However, those seeking to overcome stigmas against them can be aided by fostering relationships that affirm their positive views of themselves and of their

community, if the stigma extends past the individual level. In my third chapter, I discuss the various ways in which refugees use self-verification and self-affirmation tools to mitigate the effects of stigma.

I use the concepts of biopower and state racism in my second chapter (Mulderrig 2017; Cisney and Morar 2015). Biopower is a concept most associated with Michel Foucault (1978-79). Biopower is the control that governments or other bodies of power exert over a population. This power can come in the form of the literal, allowing or taking of life, but it can also be seen in the ways in which governments decide which members of the population take precedence over others. Biopower is often regulatory: something like the collecting of fingerprints or biological data to keep track of people. Tom Scott-Smith — a well-known figure in refugee studies — argues that the concept of biopower is misused in refugee contexts. Biopower is, in his words, a "power that is exercised over life and that operates through self-government." (Scott-Smith 2015, pp. 21-22). He argues that humanitarian aid organizations work in a top-down format, and that little self-government is really evident among the refugee populations. Scott-Smith believes that a more appropriate framework is that of paternalistic control — the aid organization as a figure which dictates and allows in a kindly way, but still one where force is applied from the outside in (Scott-Smith, 2015).

State racism is Foucault's idea that governments can exert control not only through the obvious physical means, such as maiming and killing, but also through regulatory controls (Foucault 1973; Pulido 2017; Ansell 2016; Fiaccadori 2015). Examples of this type of regulation include Jim Crow laws and racist housing policies

that segregated black and white communities. In a modern-day context, something like the War on Drugs, which many consider to be explicitly racist, could be considered an example of state racism.

I also use Victor Turner's theories of liminality and ambiguity heavily in my second chapter. Arthur Van Gennep (1909) first explored *rites de passage*, "rites which accompany every change of place, state, social position and age." Turner expanded on this concept in his essay *Betwixt and Between: The Liminal Period in Rites of Passage* (1967). He argued that liminality could be applied to larger contexts than small-scale rituals, noting: "The attributes of liminality or of liminal *personae* are necessarily ambiguous." In this ambiguous space, self-identity is often challenged or lost entirely. Turner believed that liminality can only exist for a short period of time, as it is too intense a state of being to be sustained. However, he does say that liminal communities eventually develop their own internal structure out of necessity, creating what he calls a "normative communitas" (Turner 1969, pg. 132).

In my third chapter, I use acculturation theory in a specific way (Abraido-Lanza 2016; Ferguson et. al 2017; Schutt and Mejia 2017). According to Abraido-Lanza et. al. (2006), acculturation has many definitions, but is broadly "the process by which individuals adopt the attitudes, values, customs, beliefs, and behaviors of another culture." (pg. 1342). Acculturation is generally talked about in terms of one "submissive" culture adopting the mores of the "dominant" culture. In this thesis, I choose to apply the idea of acculturation to a much smaller-scale phenomenon, and I use it to explore the ways that people adapt to the U.S. healthcare system.

I use the concept of resilience in my third chapter as well (Lloyd 2015; Sleijpen et al. 2016; Simich and Andermann 2014). Although it is not necessarily a theory, resilience is an important concept in many fields, refugee health being no exception. Lenette, Brough, and Cox (2012) say that resilience is often defined as "an extraordinary atypical personal ability to revert or 'bounce back' to a point of equilibrium despite significant adversity." I conceptualize resilience not only as this personal ability but also as actions that people take to maintain their own well-being. As Catherine Panter-Brick notes in her review of resilience literature, scholars are increasingly using more nuanced and grounded definitions of resilience, and one of these is resilience as a practice (Panter-Brick 2014).

Conclusion

The purpose of this background was to give my readers an adequate sense of the facets of refugee healthcare that I will exploring throughout the thesis. I aimed to provide a literature review that would give people a solid sense of what sort of research has already been done and what kinds of questions people are already asking about refugee health, as well as to address some of the main issues and debates that arise in the field. This chapter should give my readers the necessary factual and theoretical background for the rest of this project.

METHODS

My research questions at the beginning of this research were:

"How do East African refugees in Boston, affected by the current political climate, feel their refugee status affects their health care? What are this population's experiences with and perceptions of how providers prioritize mental health diagnoses and treatment, as compared to other kinds of care?"

I kept my research plan as simple as possible. I set the parameters of my study as follows: I planned to interview East African refugees and immigrants eighteen and up, as well as staff members of the refugee assistance agency where I interned, such as social workers and psychiatrists who are themselves East African refugees. I set a goal of a maximum interview number of n=50, and I aimed for a minimum of n=10 interviews to achieve concept saturation. Concept saturation is the point at which enough data has been collected that adding more data would not significantly alter the findings. This is difficult to achieve, but it was something I felt important to aim for. Since this would be an ethnographic study in medical anthropology, I was more concerned with the quality and rich ethnographic content of my interviews as opposed to the number of participants I was able to interview.

I intended to conduct my master's thesis fieldwork through a combination of participant-observation as an intern at the Immigrant Health Center (IHC) and through semi-structured, open-ended interviews with both refugees and immigrants, as well as service providers who are also refugees. My sampling strategies included purposive, key-informant, and respondent-driven. I expected to exclusively interview refugees that were

active clients of IHC at the time of my research, as well as providers that were current or previous employees or affiliates with IHC. The refugees and immigrants that I interviewed that were not clients of IHC were referred or introduced to me by current employees of IHC, and met the IRB-approved inclusion criteria.

I knew that IHC's biggest client base is Somalian immigrants, and thus my participants would be largely East African through no intentional design of my own. I ended up interviewing almost exclusively Somali refugees who had spent time in Kenyan refugee camps. This reflects the demographic spread of the clients at IHC.

My recruiting process consisted of three approaches: one, direct verbal interaction with clients and providers at IHC; two, word-of-mouth referral by clients or providers at IHC; and three, study-announcement flyers left in accessible areas at IHC and distributed by a handful of IHC workers. My recruitment materials were a flyer outlining my research goals, who I would be interested in talking with, and how to contact me, and an IRB-approved script for phone and email recruitment, for me to use when contacting people whom I had been referred to by IHC staff or by other refugees and immigrants. Other study materials included an interview guide with a detailed consent statement, which made clear the voluntary nature of the research, as well as my credentials, my supervision, and the steps that would be taken to keep all information confidential.

In addition to interviews, I spent approximately one year as an intern at IHC, working closely with both the mental health services and refugee resettlement services, and I kept detailed field notes as a participant observer in these situations. As an intern, I also occasionally accompanied a refugee or immigrant to a situation such as a doctor's

appointment or a Social Security appointment, to offer support and to help interpret legal jargon. Once I received IRB approval for my research, I began to attend focus groups run by the agency in which I was introduced and allowed to speak candidly with the participants involved. The focus groups covered a range of topics, from experiences getting housing to experiences with stigma as a refugee in the US.

Setting the Stage

Although the IHC moved to new offices towards the end of my internship there, I spent most of the year at the original offices. They resided in a building that was ostensibly reserved for family services, but seemed to be mostly either vacant or a mishmash of administrative offices. The building was tall and long and sparsely decorated, the major feature a grand staircase ascending through the middle. There was plenty of natural light in the building, though not, as I would find, necessarily in the offices within. To enter the building, people needed to sign in at a front desk where two friendly women would take your I.D. and provide you with a visitor's sticker in exchange. From there, you were buzzed in a locked door close to the elevators. Often, volunteers or employees at IHC were called down to pick up clients who did not have any sort of identification card, and thus had to be vouched for by a member of the organization.

The front door of IHC was flanked on either side, giving people a clear view into the office, and giving the door the feeling of being less of a barrier and more of the beginning of a yellow brick road. The floor plan at IHC was open and airy, and this facilitated the lively and dynamic atmosphere of the organization. People were constantly

joking with one another, shouting nicknames and jokes over cubicle walls in a combination of English, Somali, Arabic, and Swahili. The front of IHC is where the resettlement and administrative people work, and through a small doorway that never closes is the clinic, conference rooms, and a children's play area alongside a small sink and coffee machine. The office was painted a standard combination of off-white and beige, and cubicles were small but adequate. Fridays were the quietest days, with a lot of people leaving after lunch to attend religious services, but even so, conversation was often flowing and dynamic. Before they hired a full-time office manager, the front desk phones were manned by whoever was closest when they rang, and volunteers were free to use any cubicle that wasn't actively inhabited.

The timing of the office, on Fridays especially, revolved around prayer services, and almost all of the employees of IHC were Muslim, and most of them Somali as well. They were welcoming of any and every one; clients came from myriad backgrounds, and no one was made to feel like they did not belong or did not fit in. The culture of the organization was largely informed and determined by the people that worked there; since so many employees of IHC are East African or specifically Somali, there was a definite sense that this was an African space. However, within that space there were pockets of other cultures — the office's social worker was from Iran, and the visiting psychiatrist and volunteers were entirely white Americans as far as I could tell. Walking through the office, it felt more than anything like people were united by their common passion; cubicle walls were decorated with letters from clients, pictures of refugees' families, and dozens upon dozens of post-it reminders. The culture of IHC would be difficult to distill

into one cohesive “thing”; if I had to try, I would probably say that at first glance, it appears to be an organization by and for East Africans, but that once you dove beneath the surface of the water the depths revealed a group of people deeply involved and rooted in their community, determined to continue their calling despite all of the barriers stacked against them. Every thing that the IHC and its employees and volunteers do is grounded in this shared strong sense of purpose.

At first, I felt as though I stood out like a sore thumb, but by my third day there I felt like I was welcomed as part of the group. People visiting the office were always greeted warmly by name, and chatted with each other and employees. People often brought their own homemade food to IHC, and at lunch time it smelled strongly of spices and stewed meats, truly mouthwatering smells straight out of a restaurant. I was tut-tutted for eating Campbell’s Soup-at-Hand, and was given recipes for stews, rices, and vegetables of all kinds. At lunchtime, IHC felt more like a large home than an office.

The person I spent the most time around was Mary (pseudonym), and she was my supervisor for most of my time at IHC. Mary was an immediately eye-catching figure, often dressed in bright florals and tinkling jewelry, and had a permanently mischievous expression on her face. She had a boisterous and very friendly personality, and was always joking around with other employees and clients. Mary was also quite possibly the hardest-working person I have ever met, single-handedly organizing calendars, events, transportation; you name it. She would come into the office and yell “Kat!” as loudly as she could on a regular basis. Mary would also bring me dates to eat, insisting that students needed extra nourishment and educating me on all the reasons dates are

apparently the world's most nutritious fruit. When Mary eventually added me as a friend on Facebook, she yelled "Nice back tattoo!" quite loudly at IHC; par for the course.

After a not-very-long period of time, IHC started to feel like another home. There was a sense of camaraderie born out of a genuine desire to help people, and an undying passion for improving other's lives on the part of the people who worked and volunteered there.

What Actually Happened

I interviewed five (5) people in total, all of whom were refugees and clients of IHC. Of the refugees I interviewed, all were Somali, and all but one had spent numerous years in refugee camps in Kenya. I had anticipated that I might face difficulty finding participants due to a language barrier, and although this proved true, I was still able to conduct five full interviews that resulted in rich ethnographic data. I was also able to collect a series of "vignettes", or ongoing stories about the trials or successes of the refugees I encountered. Alongside the interviews, these vignettes tell a complex and deeply important story about the lives of the refugees at IHC.

I expected that even after a refugee agreed to speak with me they might be unwilling or reluctant to share their experiences. In fact, I found the opposite: once I was able to find people that were interested in being interviewed, they really opened up in the interview itself. Their stories were oftentimes funny, and almost always equally heart wrenching and heartwarming. In the few instances in which people seemed reluctant to share information, I let the interviewee set the pace of the conversation. I also did my best to stage the interviews as if they were a talk between old friends: we had our own room

where we had uninterrupted privacy, and we were able to relax and get comfortable with one another in a neutral environment.

The vignettes I collected came about organically, after spending so much time at IHC. For example, from month to month I might be helping someone apply for jobs or for social security, and over the course of a year I have had the privilege of seeing and helping these people from week to week, and I've been able to follow along with their progress, and to see their successes and failures. Starting my internship at IHC, I heard a lot about how such-and-such processes take forever, or how they had been trying to find a job for so-and-so and it just was not panning out. Being able to watch these stories unfold over the course of a year and tell these stories that are so incredibly common was one of the most unexpected and yet rewarding aspects of my research.

Another thing that I felt I needed to make absolutely clear was the fact that participating or choosing not to participate in my research would have no bearing on a person's ability to receive services from IHC. Since I was introduced to some of the participants through focus groups led by IHC staff, many people naturally assumed that I was also a staff member, or that answering my question was a mandatory aspect of receiving services at IHC. As well as going over the informed consent statement with participants, I also began giving an abbreviated verbal version at the beginning or end of focus groups, to reiterate the entirely voluntary nature of research participation. I also attempted to assure that participants understood their rights not only as refugees or immigrants, but also as U.S. legal residents and human research subjects.

Results

As is mentioned briefly above, my actual data derived from a total of five participants, all of whom were Somali refugees. The interviews were done entirely in informal settings chosen by the participant, as well as being at a time that worked for the participant. This ended up meaning that most of my interviews were actually at IHC, as this was both the most convenient and most comfortable for my participants. I was accepted fairly readily into the group dynamic at IHC, and the people with whom I interned were more than willing to let me observe and participate wherever I was legally allowed (for legal reasons and my lack of certain certifications, I was could not sit in on meetings with social workers or psychiatrists). This ranged from helping clients find an apartment to listening in on adult ESL lessons. During the summer, for my formal fieldwork I attended more community events, such as community English classes and events designed to foster a sense of community and introduce people, such as celebrations for World Refugee Day. People were much more open than I expected and used these events to socialize both with IHC staff and with other refugees.

In order to keep all data confidential and to protect my participants, the data was de-identified and kept secure at all times. I used pseudonyms for the study site and participants, and removed or obscured all possible identifying information. The recorder used during interviews has also been kept in a locked safe, and upon transcription all identifiable data has been erased. My participants were provided with a full copy of the consent statement and interview guide, and will be provided with a copy of my final findings. In addition, all participants were assured that their choice of whether or not to

participate would have no effect on their ability to use the services of IHC. Participants were also given a flyer outlining their rights as refugees and immigrants, as well as a list of organizations and services available to them.

Data Analysis Process and Preliminary Findings

I used a notebook and voice recorder to collect my initial data, and the voice recorder interviews were later fully transcribed and stored in encrypted, de-identified files on my computer. I used a verbatim transcription process to try and relay my participants' narratives as faithfully as possible. I began my coding process using modified Grounded Theory (mGT). Modified Grounded Theory is a coding process in which I identified overarching themes, keywords, and experiences in the data. I further took note of those experiences when I came across them in participant observation. I later analyzed overall instances of each particular phenomenon, with which I identified key concepts, assigned colors that corresponded to emerging themes, and then color-coded transcripts of my interviews and fieldnotes according to what sections of data matched which codes.

Originally, I planned to use the qualitative analysis software NViVo as my tool to code, but soon chose to switch to hand-coding to code and analyze my interviews. With regard to my field notes, I went through and gleaned particularly relevant quotes and experiences that I felt relevant to my data, and I also transcribed those in a master document on my computer, which I again converted to a PDF file in order to annotate. I created a new folder in which to store all of my annotated and coded data, and I encrypted the file in order to ensure a higher level of protection for my final data.

I applied a phenomenological approach to analyze my data. Phenomenology

focuses on lived experience such as phenomena in participants' lives, in order to view them in-context, and analyze them as they are experienced by the participant. I have been taught by my professors that a phenomenologist's job is not necessarily to interpret the words or action of a person or people, but to report and give credence to their experiences as they are, without a filter or view attached to the extent possible. I attempted to give a truthful representation of what refugees and immigrants told me about their experiences and beliefs regarding health care, without overlaying my own interpretations or my own cultural lens. This has been difficult, to say the least; as easy as it may sound, listening actively and reporting the experiences of another person without altering them in some way is very difficult. With the help of my advisor and professors, I feel I was able to give as accurate a representation of my participants' individual and collective experiences as was possible.

CHAPTER 1: THE OBSTACLE COURSE TO CARE

Individual bodies and interpersonal interactions do not exist in a vacuum. In this chapter, I will outline some of the negative experiences and issues that refugees have with their healthcare, and demonstrate ways in which those issues are systemic. Even in the case of doctor-patient interactions, which seem like an interpersonal encounter, problems are rooted in social-structural systems. In 1969, Johan Galtung introduced the idea that violence is not limited to somatic expressions like killing, but can instead be structural. In his own words: "*Violence is defined as the cause of the difference between the potential and the actual…* if a person died from tuberculosis in the eighteenth century it would be hard to conceive of this as violence since it might have been quite unavoidable, but if he dies from it today, despite all the medical resources in the world, then violence is present according to our definition." (Galtung 1969). In this obstacle course to care, elements of this violence appear whether people recognize them as such or not. This is the beginning of the bridge of refugee experience: here, people face seemingly insurmountable obstacles and are beginning the foray into the resettlement and health care process. The danger of this bridge is not in falling off of it, but in becoming stuck in it. In this way, it is almost like a bridge over a maze: if a person falls off, they may become lost forever.

The Placement of Refugees

I would like to frame refugees within structures that are political, economic, and social all at the same time. As I briefly reviewed in my first chapter, Erving Goffman wrote about stigma as any sort of attribute or behavior that distances a person from the

normative group (Goffman 1963). The expected behaviors for the normative group in a culture manifest in a set of expectations, and when people fail to meet those expectations, they are further stigmatized (Goffman 1963, pg. 2-3). For refugees, there are countless of these attributes or behaviors, ranging from the way they speak and look to their degree of unfamiliarity with things that are considered "everyday" in the U.S. Becoming a member of a stigmatized group can negatively impact the health outcomes of the individual, and may cause psychological distress (Williams, Neighbors, et. al. 2002; Heatherton and Kleck 2000).

Goffman also wrote about people as social actors - that is, through language and expression, people enact the role that they have been given in society. The "actor" that Goffman imagines is always trying to maintain their social standing by performing their role satisfactorily. They are always attempting to maintain or save "face" (Goffman 1956). Refugees are stuck in a role with limited options; they are a stigmatized group trying to gain footing in an unfamiliar social structure, and all the while they are bounded by language and the harsh expectations of others. Goffman understood that the structures in place interact with subjects in very specific ways, and that this is why social strata matter. Peoples' options are limited when they are within a social stratum which is within its own larger structure.

I suggest that this stigma and related expectations appear in the examples I use throughout this chapter. In some instances, a clinician might diagnose a refugee as having PTSD even when the patient disagrees with the diagnosis; this is a manifestation of the stigma placed on refugees and the expectation that they will have mental illnesses. In that

same scenario, the refugee might feel they have limited options: they may not want to speak out against the doctor and disagree with them openly, because they do not feel that option is open to them. In this way, they are conforming to their social role: that of someone who listens but does not question, and must trust blindly that the doctor knows best. Assumptions and imbalances on both ends of the spectrum result in a lower quality of care overall. When refugees are not allowed to break free from the role that society has imposed upon them, they are more likely to suffer for it.

Barriers to Care

There is no shortage of complaints at the Immigrant Health Center (IHC): about the slowness of the Social Security Office, about the waitlist for affordable housing, about the bureaucracy of hospitals. Both the clients and employees at IHC are well versed in the tedium that goes hand in hand with navigating government systems. Frustration is a common sentiment. I think back to a day in September: a client's application for insurance had been returned, *again*. Each time it was a new detail: a misspelling here, not having provided accompanying forms a, b, and c. No amount of speaking to representatives seemed to help. We had everything we needed to get insurance for this client, and no insurance.

The lengthy and frustrating processes refugees undergo begin before they even arrive in the United States. After refugees have been recommended to the United States for resettlement; passed their security screening, biographical collection, and medical evaluation; been granted sponsorship by a resettlement agency; and been briefed on U.S. culture and flown in, they then end up at a resettlement agency like IHC. Places like this

are often founded independently, but run with the support of limited government funding and volunteer groups. Often, people within the organization spend a considerable amount of time writing grant proposals in order to get money from charities and private organizations; the volume of requests these organizations get is high, and the chance of receiving funding is slim.

While there are many clinics set up to ensure that refugees can get basic and emergency care, getting access to regular preventative care is a lot less straightforward. Refugees with minor children are eligible for Temporary Assistance for Needy Families (TANF), and Medicaid. Refugees without children or with children who are no longer minors can use Refugee Cash Assistance and Refugee Medical Assistance. These programs last for eight months from either the time the refugee enters the country with qualifying immigration status or from the time they are granted said status by the federal government. After the eight months are up, refugees are treated the same as other low-income persons in their state in terms of program qualification (Refugee Health TA: Access to Care). Once the eight-month period is over, refugees are often still waiting for their social security or other benefits. An agency's first priority is to find housing, clothing, and food, as well as learning anything from how to use public transportation to how to work a microwave. Medical care often falls short on the scale of immediacy.

These are services that are offered to all refugees entering the United States. Refugees are sometimes given assistance for a longer period of time than other immigrants, who receive the standard eight months of assistance, but this can vary case to case. As mentioned above, once the eight-month assistance period is over, refugees are

treated the same as any other low-income group. Massachusetts follows federal guidelines for the services given to refugees, as do most states. The services offered at IHC were not specific to Somalis at all, though I would not be surprised to learn that other organizations such as local Mosques offered services according to more specific groupings. Everything that the IHC did that was not covered by federal funding – things such as English language classes and social groups — was a result of IHC soliciting grants, and relying on the help of donations and volunteers. Of the main services that IHC provides, coordinating medical care was one of the most basic and most important.

As Philbrick, Wicks, and their colleagues found (2017), coordinating medical care involves numerous pitfalls for both agencies and individual refugees, such as a lack of funding and familiarity with the health care system and language barriers (Philbrick, Wicks et.al. 2017). The authors note that although refugees are also guaranteed medical benefits for a period after their arrival, these benefits are often delayed, leaving them without care. Sometimes, patients in dire need rely on the kindness of local clinics and doctors to treat them "on account" (a term used to refer to free treatment, or treatment which will be paid for at a later date). One client of ours, just three days in the country, was rapidly losing sight in one infected eye. A local doctor agreed to treat her for free. Others are not so lucky. Private practices and clinics may opt to be generous, but this is often not possible for institutions such as hospitals, which further limits care options for uninsured refugees.

The Worst is the Waiting

We must've waited at the office for near to three hours. For such a simple status inquiry, it seems an excessive amount of time. L didn't know how to get to the office, and she doesn't speak English well enough to navigate any forms she might need to fill out. I think the idea is that our physical presence may yield better answers than a phone call. All she wants to know is whether her application is still being processed, and what the outcome looks like. I'm still completely shocked that it's taken this long to begin with. Her application for disability was sent in full nearly five months ago. It's no wonder that people here get so frustrated with the applications. I'm frankly amazed that L has been able to keep her cool at all; I'm already wanting to yell in frustration and I've only been dealing with it a day. — From field notes, May 2017

From interview with L, May 2017:

"I mean it's hard, but I just wait. That's all there is to do. Wait and call to ask. I need the social security, though. Right now I get cash assistance, and that's $280. It's not enough… my son got shot, and someone has to take care of him. I can't… [gestures] my disabilities. The extra money would really help."

"The people at the office keep telling me I just have to be patient and that it always takes time, so I just have to wait. It will get here when it will get here. I just hope they haven't forgotten me… I think they maybe forgot me."

L would end up being one of my primary participants, and by the far the one with whom I spent the most time. L is a fifty-ish year old woman, modestly dressed in neutral

and often dark colors. She walks around with a slight Mona Lisa smile on her face, but simultaneously carries an air around her of dejection, as though life has dealt her one too many blows. When you speak with her, she is kind and patient, and often chooses silence over the chatter. Her eyes are an unusually bright shade of brown, and often appear watery, though whether this is due to allergies or to emotion only she could say. She often appears distracted, like there are too many thoughts flitting through her head at one time to keep track of them all, and occasionally something seems to snag her attention – a gentle tug on the webs of thought in her mind. On the first day I meet with her, to arrange our trip to the Social Security field office, we meet in the office of the social worker handling her case at the IHC. The room is galley-style, long and tall with one narrow window above a desk at the far end. L sat on an old chair with her hands folded primly in her lap, and at first seemed reluctant to meet my eyes. After we were formally introduced and she was told that I would help her with her application, she cracked the first real smile I saw on her. We did not meet again until the day of the office visit.

Government offices all seem to look the same. The walls are a disconcerting shade of grey-white, the chairs are uncomfortable no matter how you shift, it is always either too hot or too cold, and there are faint sounds of arguing and fax machines. When I took L to the Social Security field office, I honestly (naively) expected it to be a quick trip. I merely wanted to ask someone about her application status, and I had been pre-authorized to do so. The longer we sat waiting, the more frustrated I got. It was not a busy day; why wasn't anyone helping us? When we did eventually get to see someone, it did not take more than ten minutes for them to find L's file and tell us that yes, the

application was still in processing, and no, they could not tell us why it was taking so long. L went home that day dejected — I think she had hoped that my presence might lend a sense of authority or urgency to the situation.

Refugees receive benefits such as cash assistance for up to eight months after their arrival in the U.S. There is a lack of data about the numbers of refugees that arrive in the U.S. with a disability; the consensus seems to be that whatever the population, it is underserved (Mirza 2014; UN 2017; USCRI 2017). In the time between cash assistance ending and other benefits like disability being approved, refugees are left in a situation where they must rely on others for basic needs, such as food and clothing. At IHC, staff try to set people up with jobs and stable living situations before they reach this point, but often it is not possible. Refugees in L's situation rely on the state of Massachusetts for housing, and on charities and food banks for other essentials. The Social Security Administration website states that in Boston, the wait time for a disability hearing is twelve months. In some cities, it is as high as twenty-six months (sss.gov). Over two years just for a hearing to decide if a person is eligible for disability benefits! For someone like L, who relies on the extra money that disability will provide, this is far too long.

Health care becomes an afterthought in these conditions. People use it in emergencies, but will put preventative and non-emergency care on hold. L's son was injured in crossfire from a gang shooting at the apartment the housing authority had assigned to them. He had two surgeries, and needed full-time care for a while. L herself has physical disabilities that include arthritis, and is also suffering from what she termed

"great mental pain." Both limit her ability to work. She was managing both the physical and mental pain with therapy and medications, but with a recuperating son and a small daughter to take care of, her own needs fell by the wayside. To L, the most immediate and critical the family's need for money. The sooner her disability benefits came through, the better.

The United States government is well-known for this type of bureaucratic red tape. Although during this research I had no direct experience with groups other than refugees, I can safely say from experience that the government is slow-moving and demanding for anyone, and especially for non-citizens. The most frustrating first-hand experience I had with this during my internship was with a woman who was applying for a work permit. I had been with her and the social worker when they in sent her initial application; we double checked every line, crossed our "t's" and dotted our "i's". Two weeks later, however, the full application package was returned to us with the vague instruction that we had missed one of the key forms. To our no-so-great shock, the form was indeed in the package. Perhaps they had missed it? We then individually paper-clipped every form and section of the application, to make it easier to process and ensure there was no repeat. Two weeks later, the application was sent back again: no paperclips, please! To be safe, we reprinted the entire thing, filled it out together again, providing every little detail about this woman's life, and sent it off for (hopefully) the final iteration of this silly game. As a full month passed without incident, we began to feel hopeful; alas, one month and one week in the application was returned for yet again lacking an important document. At this point, the social worker and the woman decided to apply in

person, hoping to avoid these issues. Only then did the application processing begin.

Even among people who are being helped by a resettlement agency like IHC, there are significant barriers to health care. Ramin Asgary and Nora Segar (2011) found that structural issues such as employment insecurity and limited affordability were some of the most difficult barriers to overcome. These issues are considered structural because they occur from beyond a person's immediate world; employment and the cost of healthcare are affected by national politics, the economy, and numerous other factors that cannot be addressed on a case by case basis, but still trickle down to affect individuals within those systems. Another study focusing on refugees with chronic illnesses and disabilities in the US Midwest found that the top three barriers to care were: inadequate insurance, language and communication barriers, and "a complex maze of service systems" (Mirza, Luna, et. al. 2014). Certainly, refugees working with an agency are better off; however, knowing what needs to be done does not necessarily mean it will be done.

Language and Interpretation

Once patients do manage to see a doctor, the first problem they often encounter is language and interpretation. Many hospitals do not have a live interpreter on site, or they may have one who's time is spread over dozens of patients. They instead use a video conference on a portable screen or phone for interpretation. Refugees with whom I have spoken tell me that while some translation is better than none, the screen and phone translators often fall short of the mark. In a conversation at IHC about interpretation, one woman said, "The videos are no good. They lag, or the interpreter just isn't great. The

quality is bad. Honestly, I'd prefer the Google translator thing." These technologically facilitates interpreters may manage to get across simple ideas, but may also fail to adequately explain the details of procedures or medications. Another client told me of the time that there were no translators available, either through technology or otherwise. She called her case worker, who acted as a translator instead.

I will never forget the first interview I had in which I was truly shocked. I was meeting with someone who had come to me through another IHC staff person. We met in a comfortable and quiet room with a round table and plenty of natural light, and we were drinking chai that had just been made fresh – all in all, a very relaxed atmosphere. I was still feeling nervous about interviewing, but quickly warmed up to my interviewee, whom I'll call Maria. Maria was a fashionable forty-something, with coffee-colored eyes and a quick wry smile that made it appear she was always laughing at some secret joke. She was patient with me and remarkably forthcoming, quick to laugh and joke around. Everything went smoothly, and I maintained my sense of calm until I asked if she had any memorable health care experience. Immediately, Maria began laughing, a quiet but high-pitched nervous laugh that was half hidden behind her cup of tea. She said, "Well, there was the speculum…" I immediately choked on my chai. "What?!" I said. She asked if I was old enough to have had a "woman's exam," thinking I was too young, but when I said I had indeed had the full exam, she launched into a truly remarkable story, laughing all the while. Maria was a natural storyteller, her eyes lighting up and hands waving as she described in emphatic detail her cringe-worthy first experience with the speculum. I knew she had children and asked if she had ever never had a full gynecological exam

before; she responded that in the camps, she gave birth with a midwife, and that the doctors only came by to check on mother and baby days later, so no, she never had.

Including Maria, three different women told me that during their first full gynecological exam in the United States, no one explained what a speculum was or what it would be used for. A nurse vaguely explained to one woman that a speculum was a tool used for the exam; not one provider explained that it had to be inserted vaginally. All three women described feeling pain, embarrassment, and fear:

"I thought 'Oh my GOD! What the hell is this!"

"I knew they were going to do something, but I had no idea they were going to put THAT down there."

"I had never had that before! They didn't tell me they had to put something inside of me."

In retrospect, each told her story with humor — choosing to see it as a shocking but ultimately harmless experience. But at the time of the exam, none of them was laughing. This story illustrates the fact that refugees may not feel that they have the power to question doctors, or that they have limited options in any given situation. When I asked each of these women if they had attempted to ask the doctor what was happening, one told me that she had asked what was happening, and in response got a vague, "Don't worry, it will be alright!" in response. The other two women told me that they did not feel they could ask questions at all; when I asked why, they said they did not feel that they had the authority to ask questions. One said to me, "You are supposed to trust doctors, to let them decide for you and trust them… I am not a doctor, I do not know… I cannot

question someone like that. I felt like I should just trust them."

Obviously, despite this feeling that one should "just trust" their doctor, feeling scared and lost was still the reality. The woman who had attempted to ask a question but was brushed off told me that it made her feel "like I was a child… who had to just sit back and let the adults take care of me. I wanted to know what was happening!" This feeling of being infantilized underscores the unequal power dynamics between refugees and doctors. If people are empowered to ask questions and to demand better care, they very well might. Goffman would see this is as a classic example of roles being acted out in a way that maintains the status quo: the doctor is unquestionably in charge, and the patient is ultimately helpless to do anything other than listen to their physician. This feeling of being silenced likely not limited to refugees; even people born into the biomedical system can sometimes feel reluctant to question a doctor's authority. Existing as a refugee within broader power dynamics may resulted in a compounded experience of silencing.

Perhaps my participants' reluctance to question their doctors was a result of their previous encounters with biomedical care, either in their home countries or the refugee camps in which they may have spent so much time. As Maria told me, one of the only experiences she had had with doctors in the camps was after she had given birth, when a doctor would come by sometimes days later to perform a cursory check of mother and baby and confirm that both were healthy. Overall however, my participants were reluctant to talk about any aspect of time spent in camps, deflecting any questions I asked. On my part, I was reluctant to probe, as for many people that time was an obviously

sensitive subject. One of my earlier interviews gave me the most information I was able to get out of anyone; my participant was still both verbally and physically dismissive of my questions, looking up and away or down at her hands when answering, sometimes even waving her hand as if batting away a bug. When I asked how her experiences with doctors in the camps had been, she said, "Eh, it was fine. They were good (shrugs). I only saw them a couple of times; mostly they did not see us." As a follow-up, I asked how she had felt about doctors in her home country, and if she missed that sort of care. She scoffed, again waving her hand, and said, "No! They were… it was bad. It was not good. Doctors here are much better." Again, she declined to elaborate.

That participant was the most forthcoming about her experiences, and that interview was the most illuminating on health care in the camps. Aside from Maria's comments, every other participant declined to answer questions about that period of their life, giving me the distinct impression that it was either too boring to mention, or too fraught to revisit. Because of the lack of data I was able to gather about camp experiences, I can only offer conjecture about what may have happened. If the medical staff in camps were short-staffed and the doctors overworked (as it sounds like they may have been), then it would be no surprise to learn that doctors were dismissive, even unintentionally, thus giving refugees the impression that their concerns did not warrant addressing. Perhaps also there was an air of authority projected by the doctors in the camp, and belief in the infallibility of biomedicine that almost anyone who has dealt with doctors will recognize. After all, many people that were born and raised in a biomedical system still do not feel comfortable questioning their doctors, despite their familiarity

with the system. Ultimately, the reasons my participants had the beliefs and expectations that they did remains a mystery to me.

Glenn Flores (2006) found that in 46% of emergency cases involving patients with limited English proficiency, no one used an interpreter. He also found that only 23% of U.S. teaching hospitals provide training on working with interpreters; most of the time, this training is optional. Flores states:

> "Patients who face such barriers are less likely than others to have a usual source of medical care; they receive preventive services at reduced rates; and they have an increased risk of nonadherence to medication. Among patients with psychiatric conditions, those who encounter language barriers are more likely than others to receive a diagnosis of severe psychopathology — but are also more likely to leave the hospital against medical advice. Among children with asthma, those who confront language barriers have an increased risk of intubation. Such patients are less likely than others to return for follow-up appointments to the emergency room, and they have higher rates of hospitalization and drug complications." (Flores 2006)

A different study set out to explore the "healthy immigrant paradox", which is the idea that migrant populations have better health outcomes than their non-migrant white counterparts. Ding and Hargraves (2009) found that among immigrants with a language barrier, stress conditions such as depression and anxiety were more common, especially after they first immigrated. The combined effect of the stress and the language barrier

was poorer health overall.

Patients often use family members and friends as informal interpreters, which can lead to confusion, especially regarding terminology. This practice also often puts young children and teens in the place of medical interpreter, which may not be beneficial to them. Cohen and Moran-Ellis (1999) suggest that some objections to child interpreters stem from the idea that childhood should be a time of innocence and lack of worry, and that interpretation exposes children to otherwise "adult" issues. In another study, Flores and Abreu (2003) found that ad hoc interpretation resulted in higher numbers of errors with potentially significant consequences than either professional interpretation or not interpretation at all. Many of the clients at IHC have children who speak some English, and often these children are the ones left doing their best to interpret. In California, a local lawmaker put forth a bill that would prohibit state-funded organizations from allowing children under the age of fifteen to act as translators.

Good translation is important; that much is clear. The question then becomes, what can be done at the state and hospital level to make access to interpreters a priority, especially in areas with large concentrations of immigrants?

Communication & Agency

This has been the third interview where someone mentioned a speculum. It seems like such a fundamental issue to me – during a gynecological exam, you'd think that the speculum would be one of the first things they show you and explain to you. This woman, like the other two, wrote off her experience as a simple miscommunication, one that ended in a funny story for her to tell. I'm starting to see a pattern here – somewhere in the

chain, somewhere down the line, someone forgot to stop and think, "I wonder if this person has ever encountered a speculum before?" It makes me wonder what other issues could have been avoided easily. I often hear patients here talk about a diagnosis their doctor gave them and how they don't feel like it's accurate, or they don't really know what it means. Nobody seems to feel like they can question their doctor, but they also don't seem to have complete faith in what their doctor is telling them. I'm curious about whether this could be as easy a fix as someone saying, "Do you really feel like you understand? Do you agree with what I'm telling you? Do you think something else is going on?" — From field notes, July 2017

A common complaint that we hear at IHC is that patients are "noncompliant" – they will not take their prescribed medications. Many of the refugees we work with are sent to a psychiatrist as a matter of course, and are prescribed drugs for conditions that they may have never even heard of, much less understand. For many people with whom I have spoken, their suffering is a part of life, and not something they see as a sickness which can be cured. Referring back to my earlier discussion of Derek Summerfield, it is important that doctors take into account the way their patients conceptualize their own mental illness before insisting upon a treatment plan.

Perhaps my saddest interview took place over the summer at the IHC headquarters. I once again found myself in the office of the social worker, perhaps the most unwelcoming room in the building. It was sunny and wonderful outside, but the small window with its odd placement made the room appear to be entirely blocked in, lending the feeling of a bunker. I was meeting with J, a client of the social worker who

had expressed interest in speaking with me. She was an older woman, perhaps in her sixties, wearing a matching floral abaya and head wrap. She carried a handbag stuffed to the brim with papers, overflowing with envelopes, and her phone buzzed intermittently, prompting breaks in our conversation. The interview progressed normally, if a bit haltingly. At one point, I asked if there was anything about her health care or doctors that she did not like. She paused, and thought, her head tilting to the side. She told me that she was being told to take medicine that she did not want to take. She felt she did not need pills, telling me that her doctor just did not understand the pain that she was in, that he kept trying to fix her. As she spoke about her family, her eyes welled up; our conversation was dredging up some painful memories. J told me that she felt sad very often, but that it was to be expected after what she had seen. She seemed decidedly reluctant to delve into detail about her past experiences – it was obvious the wounds were as fresh as the day they occurred. By the end of the interview, we were both crying, passing a tissue silently back and forth. I felt compelled to try and comfort her, but having no experience with pain of that magnitude, I settled for my hand on hers.

From interview with J, July 2017:

J: "The doctor gave me pills for PTSD."

K: "Do they help?"

J: "I don't take them… I don't really understand it. There is nothing wrong with my mind. They told me it is to help with my mind, but there is nothing wrong with my mind. I am just sad. I lost my family; my mother. Wouldn't you be sad as well?"

The medicalization of emotion was a common theme among clients at IHC, and is

on ongoing issue in refugee studies (see Summerfield, Tran). It did not come up in all of my interviews, but it was something that was mentioned in passing with relative frequency. It was an odd dichotomy: the employees of IHC would often casually say something like "Oh yeah, he needs to be on medication," or "They definitely have PTSD, don't you think so?" When I first started interning at IHC my then-supervisor pulled me aside and told me that all of the refugees with whom I would be working had experienced trauma of some kind, and that most of them had PTSD as a result. Keep in mind, this was the mental health clinic, so all of the clients involved were already willingly participating in the biomedical system. However, it struck me as strange that this narrative could coexist with the narrative of the refugees who complained that their doctors wanted to over-medicate them. These same refugees said doctors did not understand that their suffering was not something that could be cured. It was, to me at least, an interesting manifestation of the clash between the biomedical system and the people trying to become accustomed to it. In *Writing at the Margin*, Arthur Kleinman writes on page 12,

> "Perhaps the book's most salient conceptual point is the idea of a double mediation of distress and disease based in the placement of local worlds as intermediary between the pressure of political movements and other large-scale forces of social change on one side and the resistance or vulnerability of individuals on the other. The second mediation is the body's transformation of that locally refracted force into normal and pathological reactions." (Kleinman 1997).

Perhaps this "double mediation" that Kleinman writes about is what I was seeing at play at IHC. People were using the biomedical system to fulfill local and political obligations,

while also maintaining their own resistance to the system at large.

There was also a distinct possibility that people were playing into the narrative of being hindered by PTSD in order to more effectively make use of the cash assistance system. No one ever said so outright, but this was strongly hinted at. Once, I was sitting in on a meeting where a woman was applying for disability assistance. The social worker kept saying things like, "She had very bad PTSD, she cannot work, she needs the disability, her PTSD and some other things make it very difficult to keep a job." All the while, the woman in question was sitting silently, nodding along, not agreeing or disagreeing with anything. My interview questions did not delve into this phenomenon, and no one volunteered the information to me otherwise. However, perhaps this would be a compelling reason to "play along", so to speak, with a biomedical system that someone did not necessarily agree or identify with. In David Ingelby's *Forced Migration and Mental Health* on pages ten through sixteen, he discusses the growing doubts researchers have expressed over the usage of labels like "trauma" and "PTSD" in the immigrant and refugee community. He offers a variety of critiques from both clinicians and social scientists, writing ultimately that the concept of PTSD is too narrow, and thus acts as a reductionist filter for what is really a complex set of circumstances and behaviors (Ingelby 2006). Ingelby also writes that almost as soon as the terms "trauma" and "PTSD" became more common, so did critiques of their usage in the refugee community. This points to a broader issue regarding the "classification" of refugee experience.

The basic disconnect between clinician and patient is the direct source of a variety of problems that may appear down the line, such as the patient being marked as non-

compliant, or the patient feeling so disheartened that they cease seeking treatment altogether. Jenny Donovan and David Blake (1992) found that for many patients, what appears to be an irrational act (noncompliance) is actually a carefully balanced cost-benefit analysis that has been informed by a patient's personal and social circumstances. The authors explained that patients will weigh the costs and risks of each treatment against the perceived benefits. Donovan and Blake challenge the idea that patients have no choice but to comply with their doctor's orders; without that basic foundation, the concept of "noncompliance" starts to waver.

Linda Garro (1998) has advocated for decision-making models that take into account the "culturally based meaningful interpretation of events to actions taken in response to those events." (Garro 1998, pg. 352). She argued that the process for seeking care must be considered a culturally-constructed phenomenon, rather than one that is universal. Biomedical cultures tend to see seeking out a doctor immediately as the only logical choice, rather than one of many choices that people can make for their well-being. Garro also quotes Shweder (1986), writing "Shweder maintains that rationality is compatible with diversity and that not every rational process is a universal process." (Garro 1998, pg. 343). This quote gets to the heart of the issue: refugees who do not unquestionably follow their doctors' advice are not misunderstanding or acting irrationally; they are simply employing a different decision-making process than the one that biomedical practitioners are used to.

It becomes clear when speaking with refugees that it is not that people don't trust their doctors, or don't want to listen to them, or even that they don't believe them; rather,

it is easy to get lost in the massive amount of information being thrown at them, and become disillusioned. If a person does not understand what they are being treated for in the first place, and seeing a doctor comes with all manner of complications, then it should not come as a surprise when people cease to be active in their own health care. When someone seems disinterested in their own care, it may stem not from a lack of caring but of understanding.

A good illustration of this is missed appointments. At IHC, clients miss their appointments all the time — with us, with their therapist, with their primary care doctor. The initial urge is to ascribe personal motivations to these actions. From practitioners, I often hear, "(Patient) didn't show up *again*. Honestly, it's starting to feel like a lost cause," or "We haven't seen her in weeks. It happens. Sometimes people just stop coming." Without ever hearing reasons as to why someone missed an appointment, a lack of care on their end seems like the most reasonable cause.

In an informal interview I had with someone I knew had missed an appointment or two, I decided to ask her — carefully — why she hadn't come.

K: *"I noticed you weren't here last Friday, we all missed you! Was everything alright?*

M: "Everything is fine! I didn't have any reminder."

K: "We can call you next time! Or I can help you set a reminder in your phone."

M: "I don't have a phone, or email. I just forgot to write it down."

This is not indicative of all refugees. Many, if not most, of the clients at IHC have cell phones and access to computers. But it serves as a reminder not to assume intent.

Hannah Arendt (1955) classified refugees as being "rightless and stateless", and Giorgio Agamben thought of them as "bare life" - stripped of the identity and protections that membership in a sovereign state secures (Agamben 1995). A new line of discourse is challenging this way of thinking, and asserting that using the "bare life" narrative strips refugees of their agency, and of their right to renegotiate membership in a political body (Bousfield 2010; Bradley 2013). Allowing refugees to have a say in what happens to their bodies and their lives is essential in supporting them. A 2007 study argued that researchers must move past harm minimization, and instead seek ways to produce reciprocal benefits for refugee participants and communities involved in research (Mackenzie, McDowell, & Pittaway 2007). Michael Barnett (2012) argues that humanitarian aid is paternalistic: the aim is to "preserve and protect" human life, and this is done through intervention. Gerald Dworkin defines this as "the interference with a person's liberty of action justified by reasons referring exclusively to the welfare, good, happiness, needs, interests or values of the person being coerced." Keeping in mind the way in which refugees' lives are structured for them, it is clear how important respecting the agency of a refugee must be.

CONCLUSION

Common issues surrounding refugee health care — noncompliance, frustration, misinterpretation — can be traced back to social-structural issues. Issues that are structural are often conflated with those that are interpersonal, such as with issues of noncompliance. As Paul Farmer writes in *An Anthropology of Structural Violence*, systemic issues that play out in patient interactions often result in the patient being seen

as “problematic”. It is difficult to look past the actions of a patient or practitioner and see structural violence at play, but that is what must be done in order for any real progress to be made.

Closely examining the barriers and obstacles that refugee populations face is, and will continue to be, key to implementing policy that successfully addresses health issues in immigrant and refugee populations. It is essential that researchers regularly question long-held beliefs about these populations, as evidence has shown that we cannot rest on things that we once knew as “truths.” It is essential that governments implement plans to address the health concerns associated with a sudden influx of refugees. And it is essential clinicians and social scientists figure out how to combine their research to come up with more effective solutions to a problem that is not going away anytime soon.

Chapter 2: The Things That Are Just Okay

There is a surprising amount of ambivalence that seems to be going around. Sometimes when I ask a question or raise an issue, people have a non-response. Occasionally when talking to someone, I hit on a subject that is very personal or difficult for them, and that elicits a strong emotional response. And often I hear people talk about how frustrated or incredulous they are with "the system". On the other end of the spectrum, there are people who positively gush about their doctors or their other experiences. But in the middle of that there's a large chunk of just… nonchalance... The other day, I asked a woman how she felt about her commute to her children's hospital; she pursed her lips a bit, shrugged, and said, "Eh, it's okay. It's long. But it's fine." — From field notes, June 2017

In this chapter I will be exploring the aspects of refugee health care that are "*just okay*." These are the things that work to an extent or that people like up to a point, but that just are not quite what patients need them to be. In my background research I found a body of literature primarily concerned with complaint, and with detailing the ways in which the healthcare system fails refugees, and in my field research I heard stories of clinicians that are very effective, and whom patients adore. The challenge then was how to classify this middle ground: at what point is a service failing, when is it working, and when is it somewhere in between? Furthermore, who decides these criteria? Three specifics that I will focus on in this chapter are patient navigators, social support systems, and language learning resources for refugees. I will also identify what — or who — I see as the "key players" in the map of care, and discuss what good care might look like to

each of them. Ultimately, this chapter is intended to help illustrate the continuum of feeling that I have seen in my research: that things are not always bad or good, but that a grey area can exist in between where people have become resigned to the way things are. This is the swinging middle of the rope bridge; this is the longest-lasting and most treacherous place to be.

Refugees are caught in a difficult space: one in which they are in a place of protection, while simultaneously existing within a broader socioeconomic state of disadvantage. On one hand, they are given special legal status and allotted resources to help them adjust to life in the United States, and on the other hand they are burdened with the stigma of being outsiders and bombarded with the narrative that they are not welcome here. In between the calcified structure that refugees operate within and the successful lives they then build under that structure, there is an area of uncertainty.

Doing my internship and research during the 2016 presidential campaign and elections gave me further insight into how precarious the middle ground is. As the campaigning progressed, people at IHC were joking about how ridiculous Donald Trump seemed. We all scoffed at the idea that anyone would elect him. Prior to the election, refugees had held a difficult but somewhat stable position under President Obama — the public may not have been stoutly pro-refugee, but general sentiment was more sympathetic than not. After the election of President Trump, that steadiness became substantially more tenuous. Suddenly, the popular narrative had become rabidly anti-immigrant and anti-refugee, the President was issuing a travel ban, and people were calling IHC every day, wondering if they were going to be deported. The rigid and highly

regulated structure that they had existed within had suddenly destabilized considerably - making apparent the underlying violence it both exposed and engendered, and catapulting them further into an ambiguous space.

In the first chapter I explored how Galtung and Goffman would frame the experiences of refugees - as actors with limited options, operating within a set of rules, norms and codes that will not change, situated in a social structure that both helps and hinders them. However, Goffman also places people inside a well-established social order, not allowing for the uncertainty of a sociostructural context that shifts beneath their feet. In this chapter, I will take this one step further into the liminal space defined by Victor Turner, and into a discussion of what it means to be a biological citizen under a hostile government, using Michel Foucault's theories of biopower as a framework.

Turner expanded on Arthur Van Gennep's (1909) discussion of *rites de passage*, or "rites which accompany every change of place, state, social position and age." Turner applied this to larger social, political, and economic structures, widening the number of situations to which we can apply the frame of liminality (Turner 1966, pg. 106-107). If a person is in a specific state that is stable and unambiguous, then a person in a liminal state must confront the opposite. We can expand this to the state of being itself - when challenged, it may quickly become undefined and ambiguous.

Aid organizations, providers, and refugees alike all work within a continuum — on one end, there is a formal structure (which provides both the structural violence and the helpful resources), and on the other end are people who have successfully learned how to navigate that structure and survive, if not thrive, within it. But how do people exist when

they are, to borrow Turner's phrase, "betwixt and between"?

This is the long, long middle of the rope bridge of experience refugees find themselves navigating. In this interstitial space, refugees are being given services that help them part of the way there, but not all of the way. Contrary to some lines of thinking, agency is not lost or given up here; people are emboldened to make choices and to strengthen their own sense of self, but they do so inside a system that simultaneously validates and invalidates them. The structure in which refugees operate disallows their agency from fully developing.

Key Players and Forces

There are four major groups involved in this process of care: refugees, humanitarian or aid organizations, practitioners, and government agencies. Each of these groups has different criteria for what constitutes good and effective care, and each group also has its own concerns and agendas. Refugees want the best care and services they can receive. For the people I spoke with, bad care looks like frustrating and time-consuming bureaucracy and ineffective systems; good care looks like clinicians that take the time to get to know and respect their patients. Aid organizations like IHC want to do the best they can with the resources they have. To the people I worked with in my internship, good services were those that were available and effective, and bad services were those that were unavailable, or only available in a limited capacity. Practitioners want to be able to understand their clients and to treat them effectively. The government is a much more difficult factor to pin down, but organizations under direct purview of the government have a finite amount of money to allocate, and their concern has to include

seeing people successfully resettled on paper.

The systemic pressure that is put on non-governmental organizations — combined with the lack of funding or public support for their populations - results in situations where it looks like needs are being met on the surface, but in reality they are not. In Massachusetts, the Office for Refugees and Immigrants (ORI) is funded primarily by the federal Office for Refugee Resettlement (ORR). As stated by the ORI, "...this drives the populations we can serve." (ORI 2018). Under a government that is currently hostile to refugees and immigrants, organizations that rely on federal funding are struggling more than ever.

Social Support

Whereas immigrants generally have some measure of social support system, be it family they immigrated with or friends and family they already had at their destination, refugees often come alone or with only their immediate family. Among my participants, most had come with their children, and a couple had come with husbands as well, but few had any sort of family or other social support in place in Boston. I recall speaking in the common area to someone about his experiences with this:

H: I am very lonely, you know, it can get very lonely here. I don't have any family or friends here. Martha (pseudonym) is taking me to her church on Sunday and I am looking forward to it. I am hoping to make some friends in the city. Right now I don't know anyone.

K (me): The city can be very lonely if you don't know people.

H: Yes. I spend most of my time alone. I am trying to find a job, and trying to also go

back to school.

K: That's wonderful! School is a great place to meet people and make friends.

H: Yes! I want to take English classes, and maybe some others. I want to go to the museums with people. Where I come from we have such culture, and so much art. I want to share that with people again. I love learning about other cultures, other types of people.

K: I'm certain that you will find some people to share that with. Martha's church is very friendly, and school is full of people that want to make new friends and learn about other cultures. You'll have a full social schedule in no time, I'm sure.

It was obvious how badly H wanted to connect with people. He told me that he had been popular back home, and had a full circle of friends. Someone offered to put him in contact with a cultural group from his home country, and it was clear that the idea cheered him considerably. H was a handsome man in his twenties, dressed much like my own brother might have been: worn-in chino slacks, beat up sneakers, and a band t-shirt (The Shins if I recall correctly), complete with a messenger bag stuffed to the brim with books. He was quick to smile, and his mannerisms suggested he was so full of energy that he might burst. He talked with his hands, hopping eagerly from topic to topic: foreign films, modern artists, the greatest American authors of the twentieth century. He told me about the rich culture of his home country, all of the history that he loved to explore, all of the cultures he wanted to learn about. As he spoke, his expression grew increasingly wistful, and he began to look off into a corner of the room, rather than around the group. When he said that he hung around the Museum of Fine Arts in the hopes of meeting

people with similar interests, his eyebrows drew up and in, lending him an earnest appearance. We were speaking in an open area of the IHC offices, and by this point in the conversation a small group had congregated, all of us feeling keenly H's desire to connect with others. When the time came for everyone to return to their work, H was reluctant to go, and left with a word over his shoulder about hoping to see us all again soon.

It can be easy to underestimate the toll that a lack of friends or other social support can have on a person. When we arrive at college, we are all told that homesickness and sadness is to be expected, but that making friends will come easily. We are placed in a setting that facilitates meeting new people and exploring new hobbies. When refugees arrive in this country, in a place where they likely do not speak the language and have no established network, refugee resettlement agencies see to their most basic needs and work to establish them in some sort of comfortable life. But too often, companionship is overlooked.

Being stuck in the shaky middle ground can foster a sense of loneliness as well as the aforementioned fear and hopelessness. Goffman writes about the acting that takes place in the everyday mundane – the people that I spoke to and worked with were stuck in this mundaneness and attempting to push through to a more fully realized daily life. Theorist Michel de Certeau wrote in his book *The Practice of Everyday Life* that there are "producers", such as institutions of power, that use "strategies" to control the structures they put in place. He then posits that individual people are "consumers" acting in environments laid out by the "producers", and that these individuals use "tactics" to

navigate that structure (de Certeau 1985, chap. 7). De Certeau envisions looking down from the World Trade Center and seeing people take walking shortcuts despite the well-laid-out grid streets; to him, this is a sort of resistance on the everyday ordinary scale to the structures laid out for people.

Applying this to refugees in the process of resettlement, we can see how they are fully entrenched in the everyday mundane that has been laid out for them, having no option considering their vulnerable status. They try to push through this space creatively using the options available to them, but those options are limited and often only get them so far. When thinking of H, we see someone who is cast against and bounded by the structures that are in place for him. He attempts to reach out and connect to others that can bring him back to the self he was before he left his home country; though he feels lonely and, in some respects, forgotten, he continues to creatively push past the avenues laid out for him and to find his own way to fulfillment. Perhaps I even played a role in this fulfillment, through a conversation and a validation of H's feelings of loneliness.

There is a sense of being suspended in a state of change for far longer than is comfortable. On one hand, it can be hard to imagine feeling lonely when you witness the incredible outpouring of support that refugees receive from their communities, their churches, their new friends, and the people at the resettlement agency. There are so many resources set up to help refugees acclimate to their lives in the United States; the ORI lists thirty-five major resettlement resources in Massachusetts alone (ORI 2018), and that is bolstered by countless community groups, churches, schools and the like that have outreach programs. All of the people I spoke with knew that there were people who

wanted to help them in their journey and knew that they had support should they need it. Still, they felt ultimately alone.

For Foucault, every citizen under a governing body is a biological citizen, whose life is regulated in very real ways by the system of power relations they exist under. For some people, this regulation barely affects the life they lead: in talking about privilege, we may say that a wealthy white man has very little to fear from the current government, because it is set up to benefit him. But in order for a government to benefit some people, it has to put others at a disadvantage. To extend the metaphor, think of the United States, or any nation, like a living thing. In order to maintain the health of the whole, the government must decide what parts are healthy and what parts are not, and they must then cull the parts that are not. This results in structural, institutional racism, in which the government decides - either explicitly or not - which members of society it wants to be rid of. Foucault called this "state racism" (Foucault 1973). He argued that a government could exert power of life and death over members of its population not only through the obvious — killing, letting live, etc. — but through regulatory controls over life: the manifestation of biopower. Our government is not only institutionally racist and anti-refugee, it is now explicitly so. We can see the regulatory controls that Foucault talked about being put into place: funding is being cut, the narrative is being intentionally shifted, and questions of safety, legitimacy, and a person's right to be here and to live in the first place are being fundamentally altered.

Biopower is the control that governments can exert over people, the regulations put in place to either help or hinder their lives and movements. We see these regulations

clearly when we look at the hoops that refugees must jump through to get into the United States, and the bureaucratic red tape that they must deal with once they have begun the resettlement process. What it means to be a biological citizen in a clinic such as the one at IHC or in a hospital setting is a complicated thing. This relates to the discussion in chapter one of the medicalization of emotion; refugees are expected to fall in line with a system that they do not identify with, and in order to receive access to federal benefits they may need to construct a narrative of their own experience that emphasizes or overstates what they feel to be their own victimhood. By forcing refugees into this position, the government is exerting the sort of control over life that Foucault discusses. Miriam Ticktin (2006) examines the ways in which refugees in France use illness as a means to obtain legal residency papers. In this way, she argues: "…the sacred space of biological integrity in this ethical discourse leads immigrants to trade in biological integrity for political recognition." She also argues that humanitarianism functions now as a form of political governance, despite its insistence on its own apoliticism. This is biopower at work in refugee communities. Refugees are also biological citizens in a more immediate physical way: upon entry into the U.S., they are subjected to full physical exams, fingerprinted, and entered into a national database that tracks their movements. This echoes the biological control that Aihwa Ong saw in her study of Cambodian refugees (Ong 1995). This is a true fulfillment of the most basic iteration of what it means to be a biological citizen, and it is a pointed example of the government exerting biopower over a vulnerable and marginalized population.

Before the Trump presidency, there had been a steady undercurrent of anti-

immigrant and anti-refugee sentiment, but the government was still putting programs in place like Deferred Action for Childhood Arrivals (DACA). It seemed as though the tide was turning in favor of immigrants. During the election, candidate Trump used aggressive bullying tactics to attack communities that he saw as harmful to the country, like the newcomer (immigrant and refugee) community. When Trump was elected President, it sent a clear message that violent speech against minority communities was not only accepted, but welcome by some Americans. Whereas before, a person might not have been so vocal in their dislike of refugees, people now felt comfortable shouting things like, "go back to your country" at people on the street.

Refugees, and in particular Muslim refugees, now live under a government that is openly hostile to them - President Trump does not want them here, and he has been clear in saying so. After the election, people from all minority groups were asking, "Is this what the country really thinks of me? Do people really hate me that much?" Muslim Somali refugees experience Islamophobia, anti-immigrant rhetoric, and anti-black racism, and these prejudices intersect, creating an exponential effect. This type of perceived discrimination can have long-lasting and serious negative consequences for health (Pascoe and Smart Richman, 2009). As mentioned before, this sudden destabilization makes an already confusing and daunting system that much more frightening.

The political climate as it stands throws into relief the extreme uncertainty that refugees still face even after arriving at what is supposedly their long-term destination. Refugees have the right to return to their homeland when it becomes safe to do so, but for many people, that time never comes. A sense of dread can arise from feeling like you are

fighting to be accepted into a culture that so vehemently does not want you. The Friday after the election, the IHC office was more crowded than I had ever seen it before, and more than I have since. People lined the walls and occupied every open chair, fidgeting with their watches or skirts. Here and there, groups of people were clustered with IHC employees, speaking in rapid but hushed tones, with the occasional outburst. Phones that rarely rang were now being constantly manned. There was a sense of frantic urgency in the air, and people that had never before worried about their security were suddenly asking employees if they were going to be deported, if ICE was coming for their family, or if all of their applications for things like disability and social services were going to be automatically rejected. Everyone stood in groups clasping hands and praying, and even the children – usually running around and playing – were anxiously silent. After the election, people said such things as:

"I do not feel like I am wanted here… I feel like people are staring at me, at my kids." "I wonder if he is going to deport us. I wonder all the time."

"Someone told me he banned people from my country. From coming here, or us from going there. I am banned here now."

"I am sad that he is the President. I am sad that so many people think like this."

Goffman believed that people are categorized by their society from the first impression on, and that if society finds them lacking, they will be members of a stigmatized group. He also believed that for whatever group people are members of, there are normative expectations of them, and failure to comply with those expectations may result in further stigmatization (Goffman 1963, pg. 3). Refugees face stigma against them

every day, especially if they are visibly different. The Southern Poverty Law Center estimates that there has been a 197% increase in anti-Muslim hate groups since 2015 (SPLC 2018), and that these groups continue to be on the rise after Trump's election. They write, "These groups also typically hold conspiratorial views regarding the inherent danger to America posed by its Muslim-American community. Muslims are viewed as a fifth column intent on undermining and eventually replacing American democracy and Western civilization with Islamic despotism, a conspiracy theory known as 'civilization jihad'."

I recently attended a talk given by Dr. Heidi Ellis on trauma experienced by refugees, and on how those traumas affect their health outcomes. Stigma was a major factor discussed: being seen as an enemy with inherent negative qualities and feeling as though nothing one does will change people's minds, can result in someone's internalizing and then acting out the stigma that is placed on them (Ellis, 2018). When I asked some of my participants directly about the stigma they faced, they claimed they didn't experience any; however, a quote here or there told a different story:

"I am sorry I cannot remember, I feel silly."

"I am sorry, I know I am a slow learner."

"I don't want people to think I am stupid."

These quotes pointed to a sense among people that they are being judged, and judged harshly. The combination of feeling stigmatized and of feeling like the government - and much of the population - does not want you in the country can make people feel, at the most basic level, insecure in their sense of safety and belonging. They

feel as though the tentative hold they have on their situation may crumble at any minute. Ideally, this is when the structure would pick up the slack; instead, that sense of fragility only makes the deficits in the system more readily apparent. One of the ways in which the system does pick up a bit of the burden (with limited success) is through patient navigators.

Patient Navigators, Advocates, and Cultural Brokers

A patient navigator (PN) is defined by the American Medical Association as someone who provides personal guidance to patients as they move through the healthcare system. These people often work within the medical system to guide patients through it. Patient advocates (PA) are private citizens who help people get information and support, and do things such as find doctors that suit their needs. Patient navigators can be employed by any number of people or places: hospitals, community groups, and insurance companies are the most common. As of now, there is no regulated or nationally recognized set of credentials for patient navigators; often, PNs are volunteers. Some PNs have a background in law or medicine, but many are trained by hospitals or organizations independently. Currently, the Patient Advocate Certification Board is in the process of developing a national, regulated set of credentials for patient navigators.

In another interview with L, when I asked her if there was anything she really liked about her doctor, she looked down at her hands in her lap, bit her lip, and slid her eyes to the side — universal signs that she did not know if she should say what she was about to. She seemed reluctant to say anything, and as she was telling me about her experiences with the patient navigator, I got the distinct impression that she was not sure

if she was allowed to complain. After all, she reminded me, she really did like the patient navigator; the issue was not with that. After the following quote, L hastened to assure me that she was happy she had gotten someone at all; she was simultaneously frustrated and unwilling to voice that frustration lest she appear ungrateful.

Excerpt from Interview with L:

K: Is there anything else that you really like about your doctor?

L: Well… the first time I had to go to the doctor, they sent someone to my house to get me. She showed me how to use the bus to get to the hospital, and then she showed me where to go to get to the doctor's office. I would not have found it without her, the hospital is very [gestures with both hands] big and… confusing.

K: So you found her helpful?

L: Yes, that was very good. But the second time they did not send her.

K: Were you able to find your way okay?

L: I did eventually… but it was a lot harder. It is easy to get lost there.

In our interview, L illustrated the phenomenon of something being *just okay*: the patient navigator worked well, but the help ended too quickly. Ultimately, L was better off having had someone guide her to her first appointment but, from her point of view, the most effective option would have been a continuation of that guidance.

A 2013 study on how patient navigation affected breast cancer screening rates showed that patient navigation improved screening rates for immigrant and minority groups, but not for the refugee groups they studied: Somali, Arabic, and Serbo-Croatian. They concluded that refugees needed linguistically and culturally trained patient

navigators, so that ideally, refugees would enjoy the same benefits from patient navigation as did the other immigrant and minority groups they studied (Percac-Lima, Ashburner, et al.) A similar study (Luckett, Pena, et. al. 2015) found that patient navigators reduced no-show rates among some groups of patients — namely African-American, Hispanic, and publicly insured people. A review of community navigators in Canada found that in the U.S., the use of patient navigators has resulted in significant improvement in health outcomes for immigrant communities (Shommu, Ahmed, et. al. 2016). The body of research on patient navigators suggests that they can and do help immigrant communities, and that with slightly more specialized training can have the same effect on refugee communities as well. With this in mind, it struck me that relatively few of the people I spoke to made use of a patient navigator.

Something being increasingly explored in the field of refugee health is the idea of the "cultural broker"- someone who acts as an intermediary between people of different cultures and helps to bridge gaps in understanding. (Kirmayer, Groleau, et. al. 2003) In some ways, a cultural broker acts like a patient navigator with more extensive training: the broker is someone who is an expert in the specific cultural background and needs of the patient, and can work with practitioners to help accurately diagnose and treat them. According to the National Center For Cultural Competence, cultural brokers can be anyone from a community worker, to a family member, to an administrator, to a physician. There is no official training or certification; they are simply anyone who can bridge the divide between two cultures (The Essential Role of Cultural Broker Programs, 2004).

Laurence Kirmayer has pioneered the use of cultural brokers in psychiatry. He along with colleagues in Canada developed a "cultural consultation service" that "emphasized integrating medical anthropology perspectives with conventional psychiatric, cognitive-behavioural, and family systems perspectives." (Kirmayer, Groleau, et. al. 2003). The actual cultural consultation came in a few different forms, ranging from one-on-one time with the patient and doctor to meetings with community organizations. The service was used for forty-seven cases, and eighty-six percent of the managing clinicians involved reported that the use of a cultural consultant helped them interact with their patients better.

Although it may seem on the surface like patient navigators and cultural brokers are the same thing, they are different; one person can play both roles, but there are key differences. Patient navigators are – formally or informally – well-versed in the medical system, and can help patients of any kind through that system, provided there is no language barrier. Cultural brokers more specifically work with the unique cultural background of each patient, and there is no formal training to become one, whereas there are formal systems in place to train patient navigators.

Here is the hopefulness appearing in the system, the people who can help refugees navigate the complex ambiguities of this in-between space and see themselves safely through to the other side. As was evidenced by the interview with L, resources and people put into place to help refugees *can* come to the rescue, but they can only go so far. No participant that I spoke to said that their patient navigators had been unhelpful or that they had been better off without them, but none also felt that they had had access to that

particular resource for long enough.

Language Learning

Today was… challenging. M wasn't in the clinic today, and I finished my weekly duties early, so I was looking for someone to help. A volunteer from the church came by looking harried, and when I asked if she was okay, she responded, "I just wish we had more volunteers!" I said that I was available, so why not put me to work? "Really?!?" she exclaimed. She led me to a room where five or six people were sitting around a table. She introduced me to the other woman there, saying, "Kat is here to volunteer." The second woman looked astonished and delighted. She introduced me to the other people in the room, and at this point I still didn't know what exactly I was supposed to be helping with. She pulled me to the table and started pointing: here, this is the workbook they use, and this is the teacher's book, and these are some stories that are pretty easy. I normally start them on the vowels but don't do that for too long, you'll go nuts. I'll take the more advanced students today." At this point I realized she wanted me to teach English. I spoke up, "I'm so sorry, I usually work in the clinic. I don't have any experience teaching English." She responded, "Neither did I! Just do what seems right. You'll be fine!" — From field notes, August 2017

By the end of that three-hour session, I had managed to slide somewhat awkwardly into the role of teacher. I admit that it was extremely rewarding to see my efforts pay off with students that were newly able to write the full alphabet, or had completed a difficult exercise. My "students" asked me when I was going to return, or if I had more time to teach them. As I spoke with the students more, their strong desire to

learn and grow was readily apparent. The English class room was and is to this day a mish-mash of people, with a perpetually disorganized atmosphere. The classes are held in a small room near the front of IHC, where the teachers can see people waiting at the front door and buzz them in. A large rectangular conference table takes up most of the room, and mismatched chairs that have been pulled in to accommodate the ever-growing student body. Up against the wall near the door, there is a coat rack that is never more than half full, as most people keep their coats and bags with them. The class is almost entirely women, with vastly different backgrounds: three are friends with minimal education that help each other along, and are always laughing and talking over the teachers; one is a former pediatrician that attends with her husband, and as they already are quite proficient in English, they are often used as role models for the rest of the class. Aside from that main group, there are three or so people who come only occasionally due to time conflicts. Each and every student is earnest and eager to learn, and all of them progress at a truly impressive rate. The lead volunteer is perpetually harried, and is forever trying out new and hopefully more effective ways to teach English, while all the while working against constraints on resources. Over time, this motley crew has become close: during our fifteen-minute breaks, we laugh and exchange stories, all getting caught up on each other's lives. There is a distinct sense of camaraderie among both students and teachers, and it showcases the determination of everyone involved with the organization. All of the students wanted to meet more than once a week, ideally two or three times, but with the church volunteer the only consistent educator they had available, they had to make do with three hours one day a week. All of them were at vastly different levels, and

coordinating which exercise to give or which book to read was challenging, to say the least. Each student ideally would have had one-on-one focused attention from someone who is trained in teaching English as a second language, but although everyone in the room was keenly aware of what was lacking, they were also aware that this setup, as haphazard as it may seem, was their best choice. In her book *Politics and Poetics of Migration*, Parin Dossa writes, "…both visible and invisible veiling have prevented women from developing their potential for full participation in society." (Dossa 2004). She argues that the veil "others" Muslim women in Western society, relegating them to the outskirts, and that this veil represents an invisible veil that blocks women from participating in society. Perhaps the English classes at IHC were reflecting this: most of the students were women that wore head coverings. However, these women also belonged to a vibrant community of other Somali Muslim women. Maybe together, on the outskirts of "Western" society, they created their own new world, one in which they were "unveiled", so to speak.

Both the church volunteer and the students were highly motivated to learn English. They could see that it was possible and doable, but there was still a sense of being stuck, or of dragging one's feet through mud. As I listened to them talk to each other, one student seemed especially dismayed at her progress (or lack thereof). The others were quick to tell her that they knew it was annoying, that she would get there someday, and that all it took was time and practice, and not a small dose of patience.

On this day, I saw the sense of fear or hopelessness that being stuck in a liminal space can foster. Even though each of those women knew people who had successfully

learned English, and even though they had people encouraging them every step of the way, it felt as though they were stuck in a sand pit they would never get out of. According to the Migration Policy Institute, fifty-eight percent of refugees between years 2009–11 with twenty years or more residence in the U.S. were considered Limited English Proficient (LEP) (Capps & Newland 2015, pg. 16). In addition, only twenty-five percent of arriving Somali refugees were proficient in their native language, indicating that they did not have the educational foundations necessary for learning English (Capps & Newland 2015, pg. 14). With statistics like these, it's no wonder that people can start to feel like there's no way out.

There was a more positive commonality to be found in this situation: the desire by all parties involved to do the best they can with what they have, even if it feels like an uphill battle most of the time. I was beyond thrilled to see that when I returned from a long break, the same students that had seemed so stuck before had progressed immensely; there may always be new challenges, but being able to watch people overcome obstacles that they did not think they could surmount is like nothing else. The newer students can now look at the older ones and see that what feels impossible to them is actually quite doable. Despite the odds being stacked against everyone, people keep pushing through. Even though the situation is nothing close to anyone's ideal, they've made an incredible thing out of a daunting situation. This harkens back to Turner's idea that people stuck together in a liminal space often develop some sort of "normative communitas"; here in this space where people shared a sense of togetherness while making the most of out a less-than-ideal situation, I saw the new communitas that Turner imagined.

CONCLUSION

In this chapter, I have attempted to illustrate the ways in which stigma, structure, biopower, and liminality all interact to create a space where it can be easy for refugees to feel hopeless, lost, confused, and scared. They begin in a structure that is rigid and calcified: their options are limited. At the other end of this bridge they must cross, they see that people have made it successfully to the other side: they have learned English, acclimated to the culture, and seem to be surviving pretty well within the system. It is the middle of the bridge, where things are not so clear, that people tend to lose their footing, and they can be stuck in this middle ground for indefinite periods of time.

Yet, there is also hope in this area. Despite the structure being full of obstacles to overcome and barriers to work around, people manage to use what resources are given to them in the best way possible. As de Certeau posited, people devise and use "tactics" to navigate the structure they are place in. Some of those tactics were highly visible, even in this highly uncertain and ambiguous space. And despite the vitriolic hatred that seems to be constantly broadcasted at us, there are an astounding number of people who are willing to help, even if just in a very small way.

Chapter 3: Acceptance, Adjustment, and Reorganization (Smart & Smart 1995)

When Anna first arrived in the United States, she and other refugees with whom she had arrived were set up at a hotel by a Catholic charity. Anna had arrived with one eye painfully swollen, leaking, and she was rapidly going blind. Since she had only been in the US for less than forty-eight hours, Anna did not have insurance, money, or any English proficiency. She was directed to a local eye clinic, but was warned that due to her lack of money or insurance it might be difficult to find a doctor to look at her eye. When she arrived at the clinic, she called her case manager at IHC, who acted as translator. The case manager explained to the receptionist at the clinic that Anna was only very recently arrived from a refugee camp in South Africa, and that she had no insurance or money, but that her eye was paining her greatly. The receptionist agreed to ask the doctor to see Anna, but couldn't promise anything. The doctor agreed to see Anna, and after taking a look at her eye, was able to tell that Anna would likely never see from that eye again, but that he could help her treat the infection and ease the pain. After treating Anna with the case manager acting as translator over the phone, the doctor told Anna that for as long as he was with the clinic, she would always receive care from him, and that regardless of whether she had insurance or money, she would always be welcome there. — From interview with Anna, July 2017*

Anna told me this story with tears in her eyes, explaining to me that she felt as though she had been visited by an angel. The expression in her eyes was simultaneously anguished and grateful, and it was as if the conflicting emotions overwhelmed her body to the point that they escaped in the form of tears. She had gone in alone, unable to

communicate and unable to offer anything as payment, fully expecting that she would not receive care. Instead, she found that people she had never met were able and willing to show her compassion. Anna kept seeing that doctor until his clinic moved away from the area, and to this day says that every doctor she has seen since being in the U.S. has made her feel truly cared for.

As I have discussed in the last two chapters, in many ways the refugee experience is like a rope bridge. We have seen how structure anchors one end of the bridge, and how that structure limits the options and mobility of the people inside of it – both those who give and receive care. We have also seen how people then move from the highly rigid and structured start of the bridge to the middle of it, a shaky and ambiguous area where things are more difficult to navigate, where the potential to get lost or lose hope becomes exaggerated. In this chapter, I will take a look at the end of the bridge: this is where refugees aim to find themselves. Here, people are comfortable with their situations, and in particular, they are comfortable with their medical care.

I will be approaching this from the same theoretical framework that I used in the first chapter. I will explore the ways in which people become used to the structure they live in, how they build their agency within that structure, and how they get to a situation where, if not thriving, they are surviving quite well.

Choice, Agency, and Acculturation to the Healthcare System

M, a forty-something mother of three, exuded confidence and happiness. We met in the comfortable interview room, the round table, natural light, and fresh hot tea all once again lending itself to the feeling that this was a chat between two friends rather

than a formal interview. M was fashionably dressed in jeans, wedges, a long-sleeved blouse and a head covering, looking as comfortable in her own skin as anyone can be. When I asked if there was anything she did not like or would change about the health care system, she would simply smile and say, "No; it's wonderful." It was only when I pressed her on what she liked about her doctor that she elaborated, becoming animated as she talked about how glad she was to have found such a doctor for herself and her children. Her eyes lit up and her tea lay forgotten as she told me how much she appreciated how at ease the doctor made her children feel. Coincidentally, this is also the first interview I left feeling stymied; I had not been expecting such an emphatic endorsement of the American health care system from any of my participants, but the longer M talked, the more I found myself grinning, truly happy that she was happy as well. By the end of the interview, I felt more like a friend sharing in good news that I did a researcher.

From Interview with M, April 2017:

K: Do you like your doctor?

M: Yes, I really like him… and I love my children's doctor. We were all at the same hospital but I moved them to one closer to where we are now, out in Lynn.

K: Why did you decide to switch?

M: I thought it would be easier to get there, and I still come to Boston to see my doctor but my children's doctor in Lynn is really good for my kids.

K: What do you like about your children's doctor? Could you tell me a story about him?

M: He doesn't push them… he didn't make my eldest daughter have a full exam, you

know, because she wasn't comfortable with doing that yet. He said she could wait awhile! She was so scared to go in. One of her girlfriends had told her that she had to go get a women's exam, and that they would look at her [gestures], you know. So she was very nervous and did not want to go to see the doctor. But when we got there, he [the doctor] told my daughter that she did not have to do anything she didn't want to. And he is so patient with my kids, and he always explains things to them, so they know what he is doing. He talks to them instead of just ignoring them or talks to me. He makes them feel important.

K: He sounds amazing! How did you find him?

M: A friend told me about him… and my children, they love him. They are not afraid to go to the doctor anymore! (laughs)

I wrote earlier about the issue of agency among refugees, and about the benevolent paternalistic control that humanitarian groups and agencies often exert over them. At what point do well-meaning people and organizations need to step back and let refugees make choices for themselves?

In *The Spirit Catches You and You Fall Down,* an epileptic Hmong child (Lia) is caught between two worlds — those of her family and culture, and of the biomedical community (Fadiman 1997). Much of the conflict in the book centers on misunderstandings between Lia's doctors, Neil and Peggy, and her parents: the doctors think the parents are noncompliant, and the parents think the doctors do not understand them or truly care about their daughter. As a minor character, there is another doctor that the Hmong community favor, because he does not force them to adhere to treatment

plans; he is more lenient in his own recommendations. Neil and Peggy dislike this doctor, and believe that his behavior renders him an irresponsible physician. This debate stands at the heart of refugee health studies: at what point must people be allowed to make their own choices, even when those around them feel those choices have potentially devastating outcomes? Some may strongly disagree with the choice that M's children's doctor gave — to decide not to submit to a (strongly) recommended exam. Others may say that, ultimately, the choice must lie with the patient.

In some ways, this exchange looks like the "white-savior" argument. Two Western doctors serve a community with which they are not familiar, and this unfamiliarity causes (predictable) problems. Though they make some attempts to understand the viewpoints of their patient's parents and culture, ultimately they hold steadfastly to the belief that biomedicine is the end-all-be-all and the only answer to Lia's problem. Lia's parents chafe (predictably) against this domineering attitude. The whole story illustrates biomedicine's fight for control over the situation, and the need to establish supremacy. In an exploration of *The Spirit Catches You*, Janelle Taylor writes, "His [Dan Murphy's] description makes all too clear how medical 'competence' can be established and demonstrated by 'performing clinical narratives,' even in the face of the bleakest inability to communicate across cultural difference… To prove one's competence as a doctor, in other words, not only does not require that one 'talk with people and learn about their lives and nurture them,' but indeed demands that one steel oneself *against* being caught by 'the story of the person.'" (Taylor 2003, pg. 175). What amount of this care is for the patients, and what amount is really for the benefit of the

doctors?

Perhaps things needn't be so black-and-white. "They don't know any better" is a phrase that gets thrown around quite a bit in popular rhetoric about refugees and immigrants. This type of thinking can be infantilizing; if we think of fully functioning adults from another, non-Western culture as helpless creatures who do not know right from wrong or up from down, we are threatening not only their agency but their identity. For people from whom nearly everything — tangible and intangible — has been taken, retaining a sense of self and of choice is paramount.

In a sociological review of agency theory, Susan Shapiro (2005) argues that agency, or "acting for" relationships are necessary for a number of reasons, but one stuck out to me: "the bridging of physical, social (e.g., brokering or intermediation), or temporal distance." Ultimately, "we" (the agent, agency, doctor, etc.) are acting "for," or on behalf of, some person or persons who, for whatever reason, are not acting for themselves. The question that follows logically is then: what distances are we trying to bridge when acting on behalf of refugees?

The interview with M was unique in another way: she was the only person I spoke with who had sought out doctors other than the ones she was originally given. At the time of the interview, I thought nothing of this. In retrospect though, M seeking out a doctor that better suited the needs of her children showed a level of facility with the healthcare system that went one step beyond that of the other refugees I spoke to.

The term "acculturation" is often thrown around in reference to refugees and immigrants. Acculturation is, in lay terms, what happens when two different cultures

collide, or come into contact with one another. Often it is talked about in terms of there being a dominant and submissive culture, or of one culture "assimilating" into another (Dohrenwend and Smith 1962). In reality, a person entering a new culture may "acculturate" to some aspects and not to others; acculturation is not necessarily an all-or-none process.

In their discussion of segmented assimilation, Waters et. al. (2010) argue that there are three main different types of acculturation: dissonant, consonant, and selective. They found that dissonant acculturation is the exception rather than the norm, and that seventy percent of all acculturation could be considered selective; meaning, that is, that immigrants selectively acculturate to certain aspects of a new system rather than assimilating fully. They manage to meld different systems without forsaking one or the other. The authors also point out that selective acculturation addressed and in some ways assuaged the fears of immigrant parents that their children are "Americanizing" too quickly (Waters et. al. 2010). This concept provides an attractive alternative to the common rhetoric of an immigrant's child forgetting or "forsaking" their parents' culture. This new type of thinking is increasingly popular over older paradigms of what assimilation and acculturation look like, and it simultaneously revives and rejects the older models of acculturation by building on their foundations while radically altering the modes and effects of acculturation on modern immigrants (Alba and Nee 2003; Greenman and Xie 2008; Portes et. al. 2005).

What M did — becoming comfortable enough with a new cultural system to navigate it on her own — could be considered a sort of acculturation to the healthcare

system of the United States. When M took the next step on her own, she was not only leaning into a new system; she was reasserting her agency. She was bridging the distance herself.

A study of Somali women in Minnesota (Pavlish et al. 2010) found that many women thought their healthcare providers were insensitive, or did not take enough time with them. In M's case, as in Anna's, we find the opposite. Neither M nor Anna had doctors who were specially trained in working with refugees or who were proficient in their language; the commonality between the doctors is that they made their patients feel respected, listened to, and cared for.

"Treat People With Basic Respect"

Somewhat memorably, in writing about cultural competence, Truong, Gibbs, et. al. (2017) suggested, "we don't have to reinvent the wheel." What they meant by this was that there is not necessarily some big secret to unlock in regards to working with patients from a different culture. There does not need to be a whole new set of training to work with people of different cultural backgrounds, although that could not hurt. According to the authors, "The findings suggest that if the essential needs of clients are met, regardless of cultural background, (e.g. ability to communicate with staff, trust and a respectful and caring environment), then issues related to cultural background may be of less significance for some clients."

"Cultural competence" is the idea that providers should give services while being sensitive to the unique cultural and linguistic needs of their patients (Georgetown). An open line of communication must exist between patients and practitioners in order for

care to be optimal. The authors above, Truong and Gibbs, argue that a basic credo, "Just treat everybody with respect," gets to the heart of the issue. Betancourt (2006) underscores the fact that cultural competence is not meant to be taught in relation to one *specific* culture or group, but rather such training should teach practitioners which issues arise most commonly as a result of cultural differences. He also proposes a "framework to guide inquiry" so that people can learn from individual patients how their situation and beliefs affect and inform their health behaviors (Kleinman and Benson 2006). Being open, respectful, and patient with people may be enough to bridge the cultural divide.

This is something I have heard over and over again in my interviews and conversations with refugees. Just as in the interview with N, people have expressed to me that basic consideration is what makes their doctors good. There are three main things that all of my interviewees mentioned as being important to them when meeting with a doctor: not feeling rushed, not feeling pressured to make a decision or take a medication, and feeling like the doctor was really listening to them. Mackenzie, McDowell, and Pittaway (2007) named "taking fully into account and responding to refugee participants' capacity for autonomy" as one of two main ethical difficulties in conducting refugee research. I do not believe that any clinician would say it is difficult to treat their patients with a basic level of respect and decency. All the same, it is obviously a much more complicated issue than it sounds. There are certain behaviors that signal to people that one respects and supports them, and there are likewise behaviors that say one does not. Although vague, people can point to which behaviors made them feel cared for. So how do clinicians and other people working with refugees ensure they are sending the right

message?

There are many reasons a doctor may seem rushed or impatient with a person: perhaps they are short on time with many patients to see, or they are frustrated that a patient disagrees with them. Unconscious biases, for example, can have power over people's actions that they do not recognize (Barnes). None of the doctors mentioned in my first chapter set out to make the healthcare experience a negative one for their patients; it was not necessarily anyone's fault or failing that a person felt uncomfortable. But what can be done to mitigate the effects of unconscious bias and prejudice in clinical settings? White and Stubblefield-Tave (2016) assert that mutual trust and respect between patients and practitioners are the most important factors to overcoming health care disparities among patient populations at risk, including women and ethnic minorities. The authors came up with an eighteen-point checklist of ways to fight this health disparity; among the recommendations are: humanize your patient; identify and monitor conscious and unconscious biases; and encourage the patient to ask questions (White and Stubblefield-Tave, 2016 pg. 476-77). Trust and respect are difficult concepts to pin down. They look different to people depending on the backgrounds of the individuals and their circumstances, and this can understandably lead to misunderstandings. Perhaps the best way to establish a baseline for what these terms might mean is through an open and honest conversation between patient and practitioner. These three things sound easy enough, but they are surprisingly difficult to pull off well, especially when the patient and doctor are communicating across a linguistic or cultural boundary. Still, those three deceptively difficult things are what separate the refugees I spoke to into those who were

deliriously happy with their doctors, and those who were not. As one person I spoke with phrased it, "You just have to treat people with basic respect."

Hopefulness, Faith, and Love

From field notes, August 2017:

I've been so confused as to what I've been hearing in this research… People have been telling me that they love their doctors, that they've never experienced discrimination in their health care, that their doctors treat them well. I wanted to sit down with my internship supervisor today and ask her what her take on the situation is. When I began, I really expected to find that people were dissatisfied, or that they felt the effects of prejudice. Even when I began this internship, people told me to expect the worst, and told me that refugees have a very hard time with their health care here. I have to consider that people are not telling me the truth, or the full story, or that perhaps they don't feel comfortable enough with me to open up.

I told her my fears, and she told me that she thinks I should take people at their word. I asked her why people seem so optimistic even when they're struggling with so much, and she reminded me that what they're experiencing here is still far better than what they may have experienced before. She also told me that for many people, putting their trust and faith in Allah helps them believe that things will work in the end, and that they just need to be patient.

In an early interview with L, the woman who would become one of my main participants, we discussed the status of her Social Security application. This was before it had been in the system so long, before she felt like she may have been forgotten, before

our visit to the office. In contrast to when I spoke to her the May following this, L was much more upbeat and quicker to smile, and her shoulders did not have quite as much of a droop to them as they would come to. During this interview L periodically would say "Inshallah," almost as a mantra to repeat to herself in times of anxiety or worry.

Excerpt from conversation, November 2016:

K: Do you ever get sad or worried about this [social security application]?

L: Yes, I do. I do. I am worried when it takes so long… when I do not hear anything, that I am approved, I am nervous. I am sad for my son as well. But I know that it will take time. Inshallah, it will work out. I try not to think about it too much. I try not to. I have faith that it will work out.

In a few studies of Sudanese refugees, researchers found three common themes among people who showed resilience during their migration process: religious beliefs, social support, and personal qualities (Schweitzer, Greenslade, and Kagee 2007; Khawaja, White, et. al. 2008). Many of the participants I spoke to, as well as the people I got to know informally during my internship, spoke of faith as a major part of their life. Their faith seemed to permeate everything; in passing, people would say "Inshallah" as a matter of course. When I pressed interviewees on whether something made them feel stressed or upset, they would defer to saying, "I trust Allah. I trust that things will work. I have faith." This seemingly unshakeable faith has been shown to aid people in overcoming interpersonal traumas, such as those associated with war (Bryant-Davis and Wong, 2013). Bryant-Davis and Wong also found that religious coping - comprised of endorsement of beliefs, engagement in behaviors, and access to support from faith

communities — was associated with decreased psychological stress. The authors encourage clinicians to consider the faith beliefs and practices of their patients when working with them, and especially when confronting traumatic events.

This is not to say that faith is unshakeable, or belief infallible. As I discussed in chapter one, L occasionally feared that she had been forgotten and wondered if her application would ever be addressed. Faith seems to act as a boon for people in times of hardship; faltering occasionally and doubting does not necessarily mean that someone is not faithful, only that they are human. L was simultaneously faithful that things would work out for her, while also fearful and unsure.

Most of the people at IHC attend either church or prayer services at the Islamic Society of Boston Cultural Center (ISBCC) in Roxbury crossing. IHC recently moved venues to a building near the ISBCC, and people have been happy with the change so far. Down time at IHC resembles a ladies' tea hour more often than not: five or six women plus myself and whatever employee is free sitting around a table near the kitchenette, sharing chai and cookies. There is often casual talk about going to the ISBCC:

A: I am going to the mosque after this.

B: It's good that it is right by us now, we don't have to take the bus.

F: I used to live just up the street, and it was good to be able to go there whenever I needed, you know… to be there a lot.

People talked about the ISBCC as if it were more than just a religious center, but also a social one. They would stop in on their way to meet people there for lunch, or to attend a musical service, or a talk of some sort. Or they would just be there because it was

preferable to being alone somewhere else. Religiosity has a twofold purpose here: the belief system itself provides a mental relief, and the community aspect of religious gatherings provides social support to people. Brune, Haasen, et. al. (2002) found that firm belief systems were a predictor of better therapy outcomes, and that they were also a "protective factor" against post-traumatic disorders. In a literature review of coping strategies for East African refugees, Jessica Gladden (2012) found that religious or other belief systems were the foremost coping skill, followed by social support and cognitive reframing of the situation. Religiosity can inspire feelings of love, hope, and optimism: three things that can help people weather stressful situations.

Last Valentine's day at IHC, love (obviously) came up in a conversation among some of the women. We were sitting in the de-facto English classroom, snacking and drinking tea as we usually did on Fridays. This Friday, however, things looked a little different. The cookies were heart-shaped and pink, and around the room someone had somewhat haphazardly placed leftover Valentine's decorations, strands of shiny red hearts and cupids with bows and arrows hanging on otherwise blank walls. The students looked on with bemused expressions, not unlike those of parents indulging over-zealous children. A woman caught my eye and smirked, casting her glance towards a nearby cherub. One volunteer decided to attempt to use this day as a teaching moment: "There are different kinds of love," she said, "like the love we have for our children." Another woman replied, "I love my children. I love Allah. I love my husband." A third woman chimed in with, "Love gives us so much. You have to have love. Love for family and friends, love for God." Everyone in the group nodded sagely. Obviously, this was

something on which everyone agreed: love is a necessary part of life. For some of my participants, love and religion were inextricably tied. One woman in particular saw love as divine; she felt that Allah had graced her with the ability to love and be loved, and that the love she felt was evidence of Allah watching over her.

Celia McMichael (2002) explores this in her study of the role of Islam in the everyday lives of Somali Women in Melbourne. She argues that Islam provides a metaphysical "home" that, through informing both praxis and modes of thinking, provides relief for the women during times of hardship and emotional distress. The ability of the women to see Allah in every space and their commitment to living the tenets of Islam in their daily life grounded them and gave them something that connected them to their past lives.

This sort of comfort and regularity can be invaluable. Michelle Byng found something similar in her own research (1998): that people are able to resist discrimination and oppression through revising their own self-views. Byng posits that the Muslim community provides a safe space in which to do this redefinition (Byng 1998, pg. 473-476). I think it is important to note that hope can be seen as a practice as well as or as opposed to solely an emotion. I discuss this more in a following section; hope as it is often conceptualized is a fleeting emotion relying on external factors. However, in the lives of the participants and others with whom I spoke, hope was not only a feeling but was the undertaking of actions and the reframing of thought patterns that would allow people to grow their own sense of hope, rather than relying on others to give it to them.

It was obvious to me throughout my internship and research that in both a very

subtle yet ever-present way, religion and its accompanying emotions - love, hopefulness - were an integral part of people's ability to maintain hope optimism in the face of the myriad obstacles and barriers they were facing. Three phrases: I have hope. I have faith. I trust in Allah. These three phrases were the backbone of the resiliency that I saw in so many people at IHC, both refugees and workers. A steadfast belief that despite all odds, things will work out. Without this sense of optimism, it would be a miracle if anyone were to continue to fight to better their lives, considering blow after blow that is dealt to a person during the resettlement process. I cannot overstate the incredible importance of love and faith for my participants and the dozens of others I met and worked with over the last year and a half at IHC.

Resilience and Overcoming Stigma

Excerpt from formal interview, August 2017:

K: Do you ever feel like your doctors treat you differently because you are a refugee?

N: No, not at all.

K: Really?

N: Yeah, yes. They are very patient with me when I do not understand them, they are nice. I do not feel like they could treat me any better if I was not [a refugee], if I was from here. They are nice to everyone. And I think they treat me the same as they do all their other patients.

K: How is they treat you nicely? In what ways?

N: They smile a lot (laughs). But really, they are just so nice to me. They help me, they give me what I need, the medications I should take you know for a headache or when I

am sick. I am healthy. I don't need a lot. But the nurse is friendly, the doctor is nice, I do not feel like I am judged or like I am not wanted. I do not feel any differently because I dress differently or because I speak a different language. I think in Massachusetts, people are very accepting. There are people from everywhere here. I am not the only person wearing modest dress, or the only person speaking Somali. In my neighborhood, there are many Somali people. There is a grocery store that we can go to get the foods we want. I do not feel that different from anybody else here.

There are ten thousand Somali people in Massachusetts, with about eight thousand of them residing in Boston — Roxbury and Dorchester being the most heavily populated neighborhoods (Camacho et. al. 2014). Being at IHC, one got the impression that the people that worked there were deeply rooted in their communities, although this did not necessarily extend to the clients. Most employees of IHC have been in the Boston area for a considerable amount of time — often at least a decade — and many have family spread around both Massachusetts and the rest of the United States. For these people, I got the sense that the Somali community in Boston was like a family to them, and in support of that people often spoke of each other as though they were all relations of some sort. As I mentioned in my background chapter as well, many of the employees at IHC had friends and family spread throughout the U.S., and hearing them talk about those people makes it seem as though they are part of a large web of people that are never more than two degrees separated from each other that spreads all across the United States. On the other hand, some of the people that worked at IHC were gone once every few months to visit Somalia, and in conversations people referred to their country of origin as their

home. “I’m going home,” or “I still have family back home,” were not uncommon sentiments.

This sense of being part of a network was not as common among clients at IHC. Many of the clients, as I have mentioned previously, had little to no support systems or social networks. Although I was never told this in so many words, it seemed sometimes that being able to look to the employees at IHC, who had managed to build such networks, as inspiration or an end goal was helpful to clients. It showed people that even if they were alone in the immediacy, it did not have to be their long-term reality. Where they now felt rootless, they saw that they could eventually find themselves rooted in a community that is bigger than they ever would have imagined.

As discussed in the first and second chapters, people are routinely categorized as either part of the in-group or the out-group. Members of the out-group are stigmatized, and those stigmas can have serious consequences on the health of an individual. The ability to overcome feelings of stigma and to reinsert oneself into a comfortable social stratum is a key factor in successfully building a new life. In the first chapter, I looked at how Goffman would frame refugees as actors bound in their roles by the stigmas against them; in this chapter, those refugees have, through various processes, managed to find ways to mitigate those stigmas and to acculturate to specific aspects of their new lives.

One of the processes used to overcome stigmas is “self-verification” (Swann 1983, 1984, 2003). Self- verification “holds that people are motivated to maximize the extent to which their experiences confirm and reinforce their self-views.” (Swann 1983). Basically, this theory holds that people will seek out interactions and experiences that

support the view they hold of themselves, and that they will reject experiences that do not. This is a two-way street: people who hold negative views of themselves may seek out other people and experiences that confirm these negative views (Swann 1992). However, people that are seeking to maintain and support positive views of themselves will actively foster relationships with others that bolster those views. This is a phenomenon I have seen multiple times throughout my participant observation. The refugees I have met who are actively seeking to build stable relationships seek out communities they can rely on, such as churches, mosques, or cultural centers. Through these groups, they affirm their own existing identities while also building new ones.

Feeling as though one is not alone, as though there are people in one's community who share one's experiences and your lifestyle, is instrumental in getting through what can feel like a completely overwhelming situation. Resilience is often defined as "an extraordinary atypical personal ability to revert or 'bounce back' to a point of equilibrium despite significant adversity." (Lenette, Brough, and Cox 2012). However, those authors argue, there is also a form of resilience "as a social process arising from mundane practices of everyday life." The small day-to-day actions of building a life and acclimating to a new system are a kind of quieter resilience; one where people take things one step at a time, even when it feels like there is no possible way out of the current situation. It is going through the motions, even when they feel pointless. This is resilience as praxis, rather than as an innate personality trait.

Even when looked at through a multidisciplinary lens, resilience has some basic characteristics: "healthy, adaptive, or integrated positive functioning over the passage of

time in the aftermath of adversity." (Southwick et. al., 2014). This definition reminds me of a discussion I had during an interview with a participant who had lived through what seemed to me like an unbearable amount of loss. This interview was again with L, and the following exchange occurred after talking about her doctor's insistence that she be treated for PTSD. Although it felt distant from her at the start of the interview, and I believe she felt the same, by this point our chairs had been scooted closer to one another's and our shared sense of empathy built a connection that was not there before. L was hunched over herself, as if trying to shield her body from an invisible blow. We were both crying, and I was thinking of what a devastating blow it would be to lose what she had lost. I said to her:

K: I just can't believe it… how do you even cope? If I lost my family like that…

L: I do not want to do it. I do not want to live my life without them. But, what choice do I have? I cannot just sit down and refuse to live. I have to keep going. Every day I wake up and I cry because I miss my mother and I miss my home. I wish they were here with me. Sometimes I remember what happened, and I feel as though I cannot do anything else. I am sad always, it will not go away… I will always be sad for them.

K: How do you function with that kind of sadness? How can you feel happy again and feel like going about your life?

L: I just have to. It will not help anyone if I do not. I am not always happy. I am often depressed, especially when I think about them. But I do things even when I do not want to. I get up and I pray and I go to work and I cook. I do not feel like doing these things. But you have to. I know they would not want me to stop living because of my sadness.

A lot of people would look at this situation, where L is in a sometimes overwhelming state of sadness and despair, and would question whether this is successful resilience. Her own doctor had prescribed her antidepressants and anti-anxiety medication, which she only took intermittently, because she did not feel that she needed them. To L, her suffering was normal, and not something she necessarily thought needed to be medicated. Some would argue as to whether this behavior is ultimately positively adaptive or if it is just treading water with her head barely above the surface. Ultimately, the fact that she kept going in the face of these overwhelming emotions, and that she chose to keep living and doing her best even when she did not want to, is the greatest form of resilience I can imagine.

CONCLUSION

In this chapter I've illustrated the aspects of both life and healthcare that enable refugees to make it safely to the other side of that rope bridge that they navigate. First and foremost is the ability to find and maintain a sense of hope or optimism and to build a community that mitigates the negative effects of stigma. Second is the help of doctors that show, through any number of actions or attitudes, that they respect their patients and see them as just another human being, rather than someone to be coddled or handled. Third is the ability to exercise their own agency and to retain control over their own lives, as fully formed and functioning adults and not as people entirely dependent on others.

Ultimately, the experiences of my participants and of the people I observed during my time at IHC shows that not only is it possible to overcome barriers and carve out a place in a new society and system, it is eminently achievable.

CONCLUSION

Research Question

My original research question was simply, "How do East African refugees experience healthcare?" As my research progressed, I began to wonder why the people I was speaking to had such positive experiences with their clinicians when all of the literature I had read led me to expect strife and interpersonal conflict. I then chose to try and examine the possible reasons for so much negative reporting, and I hypothesized that researchers were conflating frustration from structural issues with interpersonal ones. Nearly every refugee I spoke to loved their clinicians; it was the stress of the resettlement process on the whole that caused them to feel lost or hopeless. In the end, I aimed to explore the full spectrum of experience that refugees go through during both the resettlement and healthcare-seeking processes.

Major Points and Findings

What I found was that refugee healthcare is not simply good or bad - it exists on a broad spectrum that ranges from completely inadequate care to exceptional care, and from intimidating clinicians to inspiring clinicians. On one end of the spectrum, which I conceptualized as a bridge, there was frustration with slow-moving bureaucratic systems, services that were either entirely absent or barely functioning, and a sense that people had lost their agency and the right to demand more of their care and of their life. I wrote about three separate women who all experienced issues with the speculum during their first gynecological exams: this illustrated the places in the healthcare structure where people were falling through the cracks. In those specific situations, things had fallen apart

at multiple places: the interpreters used by the hospital were not well-versed in the cultural background of the patients, and neither they nor the doctors were aware that the women had not had full gynecological exams before; since all of the women had children, they may have assumed that they had. The doctors did not fully explain what each instrument was and what they would be doing, something that is now done in many pelvic exams regardless of the patient's history. Most importantly, even though each of the women was embarrassed or frightened, they did not feel like they had the power or agency to ask the doctors to stop, to ask them to explain, or even to express their own discomfort.

I found that the middle, ambiguous area of the spectrum was often unexplored in the literature, and I had a fair amount of trouble deciding how to conceptualize this space. In the middle, refugees are in a state of practical liminal experience: for example, services are in place but are only effective superficially. The English language classes through the Immigrant Health Center represent such an example. In this situation, a service was being offered that was clearly better than none at all; people were getting free English education once a week, which was highly preferable to nothing. However, the teachers were all volunteers who were untrained in language education, there were not enough resources to go around, and the students wanted to be meeting more often than the volunteers were able. In a different scenario, people were being given patient navigators (PNs) to help them get to their first doctor's appointments, but the PNs were available only for that first appointment. Refugees had them long enough to learn the basics of transportation and the hospital set-up, but not long enough to really become comfortable navigating the system

alone. This liminal space has a tendency to strip people of their sense of hope and of agency. People there existed in a sort of limbo, where they had come so far since their initial arrival, and they could see that other refugees built happy and successful lives, but they could not see how they themselves would get there.

At the far end of the spectrum, people found success in multiple areas. In this area, services did what they were supposed to do, and people became comfortable in what had originally been a daunting and overwhelmingly foreign system. In one example, a woman I spoke to explained how happy she was with her and her children's doctors. She told me that she had switched hospitals and sought out those specific doctors on a recommendation from a friend. She explained that she liked her children's doctors so much because they really took time to get to know her children and to listen to them, and he did not pressure them to do anything they were not comfortable with. The commonality among all of the doctors beloved by their patients was a sense on the part of the patient that their doctor truly cared about them and respected them as human beings, and as people capable of making informed and intelligent decisions. At this end of the bridge as well, people have managed to overcome or mitigate a significant amount of the stigma placed upon them. They have found ways to foster hope, love, and positive relationships and to maintain a sense of normalcy in their everyday lives that helps them successfully rebuild their identities.

This not to suggest that refugees all make it out of this liminal space to find happiness and satisfaction; it is entirely possible that they are stuck in a fearful sense of uncertainty indefinitely. During the course of my research, I saw that is was indeed

possible to move across the bridge. However, possibility does not guarantee fruition. I believe that for many of the refugees I met who were stuck in that frightening space, seeing others in their community build successful lives served as a source of hope and motivation. Still, with so many odds stacked against this population — stigma, threats from government, etc. — it will for the time being remain a rocky road to contentment, if people manage to get there at all. For the time being, people remain on the rope bridge, suspended indefinitely, swinging in the wind.

Another major theme I found was that issues were not as cut-and-dried as they first appeared to be. In one example, I discuss how clinicians often thought that patients were being non-compliant out of a lack of respect for the doctor's judgment or their own health; in reality, patients were making much more well-thought-out and complicated choices about their health than doctors gave them credit for. When a patient refused to take their prescribed psychotropic medicine, it was not out of any malicious intent; the doctor and patient merely disagreed on what constituted a mental health issue and on how any issue should be treated. Due to a number of factors, such as linguistic and cultural barriers, they had not built the kind of relationship where the client felt that they could question the doctor openly, and the doctor had not fully considered the client's own background and meaning systems when diagnosing and prescribing a treatment.

Theoretical Framing

I used a number of key theories and ideas, the most important of which were: Johan Galtung's theories of structural violence; Erving Goffman's theories of stigma and the presentation of self; Michel Foucault's theories of biopower and state racism; Arthur

Van Gennep and Victor Turner's theories on liminality and ambiguity; and William Swann's theories of self-verification. I also used writings on resilience, somatization, cultural competence, and patterns of health seeking and decision making.

I attempted to synthesize these theories to create a cohesive view of the worlds and experiences of the refugees that I worked with and spoke to. I situated refugees within a structural framework that enacts violence upon them, and I also framed them as social actors in a role that is highly stigmatized. I then discussed how they enter a liminal state during the process of resettlement, and how this can lead to feelings of futility or hopelessness that they must then work to overcome. In my discussion of stigma, I also talk about the effect that being a biological citizen under a hostile government may have on health, and how this is magnified by the aforementioned sense of ambiguity. Following this, I use theories of resilience and self-verification to highlight the ways in which refugees overcome the difficulties they face and how they reframe and reconstruct their experience and identity.

Practical Outcomes, Further Recommendations, and Questions

I hope that this study helps to elucidate some of the nuances of refugee healthcare. After seeing that the existing literature lacks reports of positive experiences, my main goal was faithfully reporting the things that my participants loved about their healthcare while simultaneously not undermining the very real issues that there are with the resettlement and healthcare systems.

Part of making sure that refugees have acceptable health care is convincing the public and governments that large populations of displaced people are not going to

suddenly disappear; the problem will not solve itself. Refugees are going to keep fleeing to safer countries whether people like it or not, and governments *must* learn how to handle sudden influxes of immigrants. Choosing not to do so creates not only a humanitarian issue, but a massive public health one as well. Many governments no longer have a choice in whether to accept refugees and deal with the crisis. The crisis is being thrust upon them and it is impossible to ignore. Neither can governments simply build a wall to keep people out; people will find their way regardless.

I found that people often neglect to examine phenomena closely enough, and thus end up attributing issues or behaviors to the wrong thing, or only clearly seeing part of the picture. The experiences of refugees that are resettling and navigating a new healthcare system are frightening and complicated, and answers will not be found by issuing blanket statements or by pointing fingers at any single group of people. Parin Dossa (2004) warns against the use of a "deficiency discourse"; a way of framing refugee experiences as pitiful when seen through the lens of Western social forces and societal institutions. Reducing an extremely complex situation to any sort of deceptively simple frame can only harm rather than help anyone involved. If I could choose any one thing for people reading this thesis to take from it and remember, it would be that there is a clear pattern of behavior that distinguishes the practitioners that my participants came to trust and cherish: the ability to make patients feel listened to, respected, and cared for; to make them feel like they were not being treated any differently because of their status as a refugee and immigrant; and to show them that their thoughts, beliefs, and agency matter. They matter.

I believe that further research into the role of memory would be beneficial. So many of my participants were reluctant to speak about their time in the camps, or their lives in their home countries, and not having that information makes it more difficult to get a holistic view of refugees' experiences. It was clear for many people that that time in their lives was difficult, to say the least. For the refugees themselves, neglecting to address those potentially traumatic memories could hinder their ability to recover and to move across that ambiguous middle section of the bridge. For many of my participants, interactions with doctors in their home country or the camps may also have been difficult and established a framework in their mind as to what a Western biomedical doctor was. I believe that studying the role of memories of previous encounters with biomedicine could offer insight into the distrust that many refugees seem to feel around their clinicians.

I also believe that theories of liminality and ambiguity should be more closely explored. During my initial research, all the literature I found discussing these focused solely on the experience of refugee camps as a liminal space; I suggest that this feeling of ambiguity continues long after refugees leave camps, and that the uncertainty it fosters affects the ways in which people then lead their lives during and post-resettlement. I suggest revisiting the theories of Van Gennep, Turner, and others and expanding theoretical research into the liminal experience, and in particular into extended ambiguity as opposed to liminality as something that is purely transitional. I assert that people can become stuck in a liminal space, and that this phenomenon deserves more examination.

Further questions that I think would be worth exploring include: How could we train clinicians to examine their own unconscious biases and to mimic the successful

behaviors that I saw in my research? Working on the assumption that I am not the only person to hear stories of positive experiences with healthcare workers, why is the literature around this issue largely negative? What are the distinct ways in which the resettlement and healthcare systems are succeeding in helping refugees and immigrants, and how can we expand and build upon those successes? Specifically, I have written about how the assets of cultural centers like the ISBCC and local NGOs provide tools and spaces for people to counter the structural forces that impinge their ability to enjoy a stable life. How can those places and the assets they provide be built upon and protected? And finally, what can we do to mitigate the effect that things like structural violence and state racism have on the health of marginalized populations?

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